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Concetta Triglia
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# An Interpretive Phenomenological Analysis: Exploring the Experiences of Eye Bank Coordinators When Approaching Families of Decedents for Eye Donation

By: Concetta Triglia

A Dissertation Presented to the Dr. Pallavi Patel College of Health Care Sciences of Nova Southeastern University in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Nova Southeastern University

2018

**Nova Southeastern University**

**Dr. Pallavi Patel College of Health Care Sciences**

We hereby certify that this dissertation, submitted by Concetta Triglia, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the dissertation requirement for the degree of Doctor of Philosophy in Health Science.

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# Abstract

This dissertation was used to addresses a group of individuals who work as eye bank coordinators. These individuals call families and approach them for eye donations from a loved one who has just passed away. An interpretative phenomenological analysis (IPA) was used to explain the lived experience of eye bank coordinators who call families for consent of eye tissue. The focus was to understand the dedication of the coordinators to giving the gift of sight and exploring the positive and negative experiences of eye bank coordinators. IPA is used for a keen understanding of eye bank coordinators, and the investigator gained insight as to why their role and well-being is important to eye banks by conducting and analyzing the interviews through the lived experiences of eye bank coordinators. The theoretical underpinnings of this research were based on the theory of planned behavior and self-perception theory. Four participants were interviewed as to their positive and negative experiences in their daily work. The research questions were What are the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families (RQ1)? and How do the positive and negative lived experience of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families (RQ2)? Encountering positive and enthusiastic family donors, needing to understand the situation or grief of family members, encountering closed-minded family members, and limited negative encounters experienced were the main themes that addressed RQ1. The main themes that addressed RQ2 were having the energy and motivation to seek for more donors, ensuring the right information was conveyed to the families, feeling more relaxed and comfortable, continuing to explain and ensure the correct information was conveyed, coaching and collecting oneself back, knowing how to read the actions and reactions of families, and learning from experiences and becoming more cautious.

# Acknowledgements

I am in complete gratitude to have had the opportunity to interview and research the four participants within this study.  I was honored to be able to listen to their stories and for them to have openly shared their experiences as a source of knowledge and insight into their daily challenges and accomplishments as eye bank coordinators.

I would like to thank my dissertation chair Sarah Ransdell, PhD, and dissertation committee members Terry Morrow Nelson, PhD, and Dana Mills, PhD, for their guidance and support throughout the years for they allowed this work to prosper.  I am privileged to have had their wisdom and knowledge as examples throughout this process.

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# Chapter 1: Introduction

## Problem and Domain of Inquiry

The Eye Bank Association of America reported that 76,431 corneal transplants were performed in 2014 and over 1.5 million transplants were performed since 1961 (Eye Bank Association of America [EBAA], n.d.-a). These corneal transplants would not be possible without the generosity of the donor families and the tireless efforts of eye bank staff. The approaches for obtaining consent for both eye and tissue donations differ vastly from organ donation. Families of organ, eye, and tissue donors suffered the sudden or unexpected death of a loved one due to cardiac arrest, stroke, motor vehicle accidents, drowning, suicide, homicide, or industrial and home accidents (Hogan, Coolican, & Schmidt, 2013).

Organ donor coordinators have to interact with these family members, who are experiencing extreme emotions with the sudden death of a loved one. These organ coordinators are at the hospital and are able to build a rapport with the families for days prior to approaching the families for consent. They are also able to access the family's interactions with the hospital staff, understand the dynamics of the family, and understand the readiness for accepting the death of a loved one. The task of an eye donor coordinator is to know how to sympathize with the family members while enlightening these individuals of the benefits and significance of eye donation. Therefore, the research questions of this study will explore the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families.

Compared with organ donation, the process of eye donation is more complex and difficult for the coordinator; these differences include timing of the request and face-to-face versus telephone consent (Hogan et al., 2013; Rodrigue, Scott, & Oppenheim, 2003). Unlike organ donation, which can take place in the hospital where the donor is located, eye and tissue donation occurs posthumously, and the body may have already been transported to another location by the time staff is able to screen and contact the family. The eye bank is notified of the death and screened to determine medical suitability. Once eligibility is determined, the eye bank coordinator will then contact the family by telephone and discuss the possibility of donation. The family must be contacted, and the tissue should be recovered within 12 to 24 hours after death. Because the eye donor coordinator may not have had the experience of interacting with the family personally, he or she may have failed in establishing a relationship with the family (Hogan et al., 2013). Therefore, family members have differences in the perceptions of organ donation process and the tissue donation process, which affects the experience and decisions of family members (Hogan et al., 2013; Rodrigue et al., 2003).

The coordinator must also be aware of the factors or signs to look out for in order to avoid offending them in a possible time of grief and to identify a family that is most likely to say yes to eye donation. Stouder, Schmid, Ross, Ross, and Stocks (2009) were able to name factors that identify a family that is most likely to say yes to organ donation. These factors include (a) they understand that their loved one is dead (95%), (b) they have been given enough information about donation (93%), (c) they felt that the approach was made at an appropriate time (86%), (d) they were treated respectfully at the hospital (83%), (e) they felt that their loved one received good care (74%), and (f) 50% had previously discussed donation with the donor. These are the factors that the eye donation coordinator must be aware of to improve the chances of acquiring a positive response from the family of the deceased and maximize donation.

In 1986, most states adapted the required request law or routine inquiry law. This law obligated hospital staff to approach families if the potential donor was deemed acceptable for organ, eye, and tissue donation (Farge, Silverman, Khan, & Wilhelmus, 1994). Based on this law, physicians and hospital staff are tasked to approach families after a death occurred for eye and tissue donation. Nurses were the key people to approach the family and talk to them about donation and the process. Their beliefs, knowledge, and attitude towards donation could affect a family's decision to donate. According to Ingram, Buckner, and Rayburn (2002), nurses are critical to increasing organ donation. The researchers found that although the nurses had positive attitudes in organ donation, they did not act on their beliefs and approach families for consent (Ingram et al., 2002, p. 254). The reason for this disparity may be due to the fact that hospital staff, unlike a donor coordinator, do not have any training in approaching families and are uncomfortable when trying to bring up the subject. Several researchers have shown that medical students and nurses have no training during their course work about donation (Ingram et al., 2002; Zheng et al., 2012).

The most common route used in the United States (US) to approach families for eye and tissue donation is phone calls to families (Hogan et al., 2013; Verble, Darcy, Penta, & Worth, 2013). Staff members or donation coordinators are trained to speak to family members over the phone to obtain consent and conduct a medical and social interview about the deceased loved one. However, it is difficult to know how the family is grieving with just a phone conversation. Stouder et al. (2009) highlighted that coordinators may have a difficult time understanding the feelings or perceptions of the bereaved family and knowing if they have enough information about the donation while showing compassion and sympathy when making the approach over the telephone. This barrier sometimes causes a delay in approaching the family, obtaining consent, and ultimately, obtaining the tissue for transplant.

Giving the family time after the notification of death may result in increased eye donors. Niles and Mattice (1996) suggested that families must be given enough time to accept the death of a family member before they are presented with the option of donation. The timing of the approach for donation might be critical in obtaining consent from families (Niles & Mattice, 1996). When the eye bank donor coordinators approach the families for consent, they often ask for more time while they talk to other family members about the possibility of donation. On the other hand, there are some families that make a decision immediately and need no time at all to make a decision. This difference may be based on previous experience (positive or negative) with donation, prior knowledge (fact or myth), cultural belief, or religion.

The coordinator's perception of the family's reaction is important in the success of the possibility of donation. Rodriguez-Villar et al. (2012) studied the coordinator's perception of next of kin's reactions during family approach for tissue requests and its correlation to donating tissue and refusal to donate. The researchers found that families reasons for accepting donation were utility (29%), solidarity (11%), kindness (3%), and continuity (0.8%); the remaining used several of the arguments and reasons for rejecting donation were presumed refusal in life of the deceased person (30%), did not want the relative to be touched (25%), no particular reason (19%), did not want to make decisions because the lack of the deceased's will (15%), and the remaining 11% included conflict with the health care system, religious arguments, and other (Rodriguez-Villar et al., 2012). The researchers also found that 67% of the interviewed did not manifest surprise, 27% manifested disapproval, and in 36%, there was a positive previous donor's agreement to donation. In 94%, there was an understanding of tissue donation, and in 64%, there was immediacy of the final decision (Rodriguez-Villar et al., 2012). Finally, the researchers were able to demonstrate that 22% of those who manifested surprise at the request gave approval for the donation, whereas 55% declined donation (Rodriguez-Villar et al., 2012).

At this time, there is a gap in literature in terms of addressing the attitudes and beliefs of the eye bank coordinators who speak with the families to approach for consent. However, most researchers focused on considering factors related to the families and donors themselves, such as identifying potential eye donors (Johnson, Dutch, & Knott, 2016), and determining the signs from families that make requesting for eye donation more effective (Hermel et al., 2015). Researchers failed to highlight the fact that eye bank coordinators are tasked with calling families at a vulnerable time in a family's life, which may pose challenges on the part of the eye bank representative. The attitudes and beliefs of the coordinators may influence the families' decision to consent or not to consent. It is imperative that the coordinator is able to answer all questions for the family and to be compassionate when approaching for consent. In the succeeding sections of Chapter 1, the discussion will be focused on the development of a problem based on the research gap and the research aspects related to addressing the problem established for this study. The problem is generally about the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families. This researcher will explore these lived experiences, both positive and negative, through interpretative phenomenological analysis (IPA). IPA is a method that looks to examine the larger significance of lived experiences by developing interplay analysis of the description in relation to social, cultural, and theoretical contexts (Callary, Rathwell & Young, 2015).

## Problem Statement

The general problem is that it is difficult it is to assess the family's progress in the grieving process when calling for eye donation consent (Hogan et al., 2013; Rodrigue et al., 2003). The roles and responsibilities of eye bank coordinators require them to deal with families undergoing complex set of emotions. Calling families too soon after the death of a loved one may offend and discourage the families from donating eyes for transplant. On the other hand, calling too many hours after the death sometimes makes reaching the families nearly impossible. The eye bank coordinators have the daunting task of calling these grieving families at that the most difficult time of their lives. This complexity of family members' emotions can be seen in the responses to requests for donation, wherein not all of the responses are positive, thus making the job of the coordinator difficult. These experiences have an implication for the performance of the eye bank coordinators as they do their work. Exploring the attitudes and perspectives of the eye bank coordinators before they make the call and during the call may help the program directors to address those concerns and help their employees with deal with families. The specific problem is that the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent are unknown. Their specific experiences with families (positive or negative) could affect their ability to continue approaching next of kin to obtain consent for eye donation.

## Purpose of Study

The purpose of this phenomenological study was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. The investigator found meaning in their lived experiences by conducting phone interviews about the phenomenon of requesting for permission for eye donation from the bereaved family members during the grieving process. Currently, there is little that examines the experiences of the eye bank coordinators before, during, and after making the phone call to request for donation from the families. Based on the purpose of this study, research questions were developed to provide specific and explicit focus on the aspects for the problem that were answered for this research. The research questions were focused on positive and negative experiences of eye bank coordinators when interacting with bereaved families of prospective donors.

## Research Question

The specific problem is that the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation are unknown. The purpose of this phenomenological study was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. To address the problem and achieve the purpose of this phenomenological study, the overarching research question is the following: What are the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families?

The theory of planned behavior states that an individual's belief is associated with a specific behavior (Ajzen, 1991). Moreover, as seen in Figure 1, a person's attitude toward the behavior, subjective norm, and perceived behavioral controls influence the individual's behavioral intention (Ajzen, 1991). The concepts involved in this theory is related the current study as it guides the researcher in analyzing the decision and manner of communication of the eye bank coordinator towards the bereaved family.

The researcher will look into the three components of the theory of planned behavior: attitude toward the behavior, subjective norm, and perceived behavioral controls (Ajzen, 1991). These three components will be essential when exploring the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families and when adjustment the strategies for requesting permission from bereaved families, which reflect the two research questions of this study. Based, on the problem of the study, in the context of the theory of planned behavior, the specific research questions are the following:

1. RQ1. What are the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families?
2. RQ2. How do the positive and negative lived experience of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families?

To accomplish this research the resources that will be used are Coordinators from three eye banks across the country were the resources used to accomplish the research.

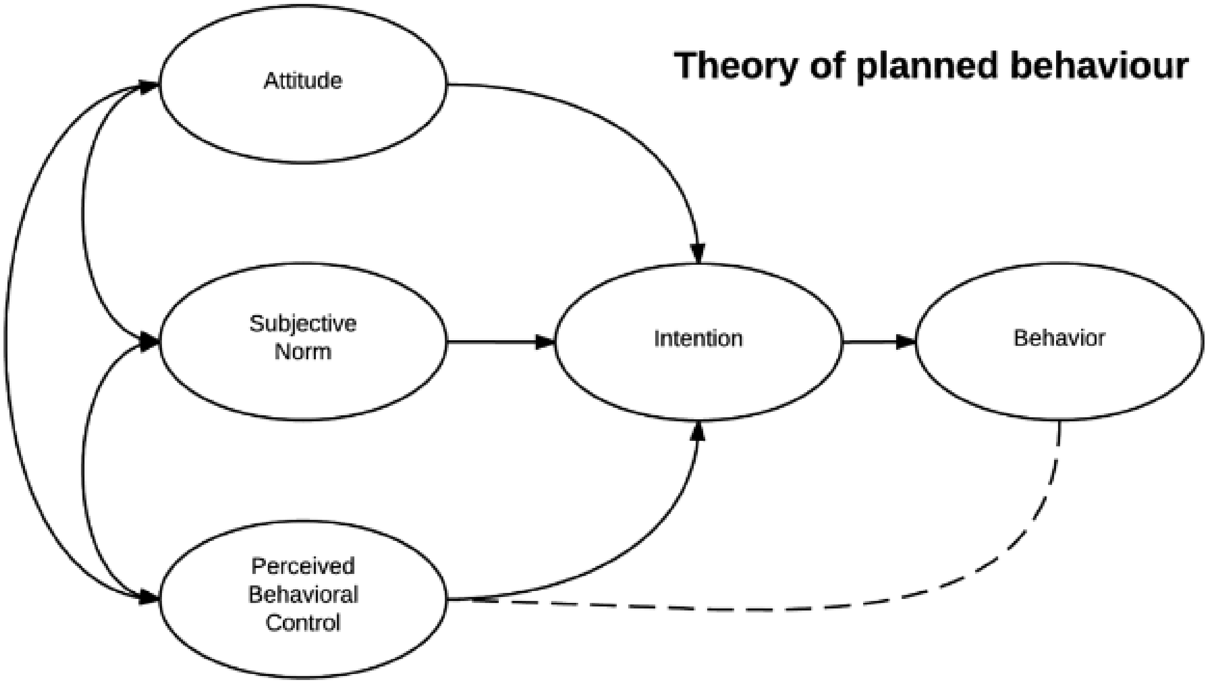

*Figure 1*. Ajzen's Theory of Planned Behavior

## Nature of the Study

With interpretative phenomenological analysis (IPA), the larger significance is examined and has three components: phenomenology, hermeneutic, and ideography (Callary, et al, 2015). IPA was appropriate because the purpose of the study was concerned with exploring how eye bank coordinators make sense of their lived experiences related to obtaining consent for eye donation from the bereaved family of a potential donor (Callary et al., 2015). The phenomenological component was guided by Edmund Husserl who was concerned with careful examination of human experience; particularly, in finding a means by which someone might come to accurately know the experiences of a given phenomenon and would do so with a depth and rigor, which might allow them to identify the essential qualities of that experience. If the identification could be done, then Huesserl reasoned that these essential features of an experience would transcend the particular circumstances of their appearance and might then illuminate a given experiences for others too (Smith, Flowers, & Larkin, 2009).

The ideography component of IPA is concerned with the particular. The commitment to the particular functions on two levels: "There is a commitment to the particular, in the sense of detail and therefore the depth of analysis and to understanding how particular experiential phenomena have been understood from the perspective of particular people, in a particular context" (Smith et al., 2009, p. 29). Therefore, IPA uses samples that are small, purposefully-selected, and carefully-situated. Four participants were recruited for the data collection part of the study until data saturation was reached. In relation to IPA, the theoretical foundation used for accomplishing this phenomenological research included the theory of planned behaviors and theory of self-perception in relation to exploring positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families.

## Theoretical Framework

The theories used as foundations of the theory were planned behavior and theory of self-perception. The theory of planned behavior presents that an individual's belief is associated with a specific behavior (Ajzen, 1991). Moreover, a person's attitude toward the behavior, subjective norm, and perceived behavioral controls influence the individual’s behavioral intention (Ajzen, 1991). Attitude toward the behavior refers to the degree to which a person has a favorable or unfavorable evaluation or appraisal of the behavior in question. A person’s subjective norm refers to the perceived social pressure to perform or not to perform the behavior. Finally, the perceived behavioral controls refer to the degree of perceiving that a person has control over any given behavior (Ajzen, 1991; McEachan, Conner, Taylor, & Lawton, 2011). This concept was related the dissertation study as it guided the investigator in analyzing the decision and manner of communication of the eye bank coordinator towards the bereaved family based on three components of the theory of planned behavior: attitude toward the behavior, subjective norm, and perceived behavioral controls (Ajzen, 1991).

Self-perception theory presents how individuals develop personal knowledge about their own attitudes, emotions, and other internal states by making observation-based inferences of their own behavior and/or the circumstances in which this behavior occurs (Bem, 1972). For example, the observation of an individual about personal behavior is the partial basis for the person’s own recall of previous events, feelings of shock-produced discomfort, and other beliefs and attitudes (Bem & McConnell, 1970). For the dissertation study, the self-perception theory guided the investigator when analyzing the decision-making process of eye bank coordinators for decisions for uncomfortable and difficult situations when communicating with the bereaved families. The theory of self-perceptions presents that the researcher to not only focus on the behavior of the bereaved family, but also on the perception of eye bank coordinators about personal capabilities as they communicate with the family members.

## Significance of the Study

The significance of the study was to provide information to eye bank executives for understanding the experiences of staff, specifically eye bank coordinators, when talking to grieving families.

## Practical Applications of the Findings

From the experiences at the Florida Lions Eye Bank, the coordinators have faced some challenging families when approaching them for eye donation. It has been difficult for these coordinators to overcome these challenges. These shared experiences among eye bank coordinators have never been explored or discussed. When eye banks are developing training programs for eye bank staff, the findings of this research can be applied when approaching families for dealing with the daily challenges they face during conversations with family. Eye banks can also apply the information from this dissertation study when helping coordinators deal with families and the grieving process. These findings can be used when interviewing potential eye bank coordinators. Executive directors may look for previous experiences, attitudes, beliefs, and knowledge regarding eye donation.

## Theoretical Contributions

The theories used as foundations were the theory of planned behavior and theory of self-perception. The findings of the dissertation study included the perceptions and experiences of eye bank coordinators, which were used to explain the theory of planned behavior and the self-perception through an example within the field of communication, specifically, for organ donations. Therefore, the findings of the study also have theoretical implications and significance in terms of expanding the scope of applicability of the theory of planned behavior and the self-perception theory.

## Barriers and Issues

While conducting this dissertation study, there were many barriers that the investigator encountered may encounter. The investigator made the assumption that the coordinator was willing to share negative experiences, difficulties discussing eye donation, the consent process with grieving families, and the coordinators own attitudes and beliefs regarding donation. Finally, families feel more comfortable with coordinators who are knowledgeable and show compassion. It was difficult for the investigator to determine the coordinators knowledge and compassion when speaking with families.

## Research Tradition

To explore the lived experiences of eye bank coordinators who approach families of decedents for eye donation, the investigator used a qualitative approach for understanding this phenomenon. The phenomenology research method the investigator used interpretive phenomenology analysis. Phenomenology research was used for the investigator to understand the lived experience about a phenomenon as the participants described as well as gaining a deeper understanding of an eye bank coordinator's everyday experiences (Creswell, 2009; Patton, 2015; Smith et al., 2009). Interpretive phenomenological analysis is concerned with the detailed examination of lived experiences; this examination occurs in a way, which enabled the researchers to express lived experiences in its own terms, instead of expressing them based on predefine category systems (Smith et al., 2009). The researcher developed a semi-structured interview for four participants. The eye banks that participated in this study were San Diego Eye Bank, Lions Eye Bank of Nebraska, and the Florida Lions Eye Bank. These eye banks were chosen because of being located in different geographical location. Each eye bank was located in a different time zone, which provided a broader range of perspectives across the country. The investigator also developed an invitation letter to the executive directors of the participating eye banks. The participants had a minimum of 1 year (12 months) experience working for an eye bank and approaching families for eye consent. Once the executive directors agreed to participate in the study, eye bank coordinators were invited to join the study through another invitation letter sent via electronic mail. A consent form was emailed to the interviewees. There was an initial interview with the participants and then a second follow-up interview. Once the data were collected, the investigator analyzed the data, identifying similar themes between the participants.

## Definitions of Terms

1. Bereaved family. The bereaved family is composed of a group of individuals, who are immediately related to a deceased person considered for eye donation.
2. Cornea. "The cornea is the eye's outermost layer. It is the clear, dome-shaped surface that covers the front of the eye" (EBAA, n.d.-b, para. 1).
3. Corneal blindness. Occurs when the cornea becomes cloudy; light cannot penetrate the eye to reach the light-sensitive retina, which results in poor vision or blindness (EBAA, n.d.-b, para. 2).
4. Cornea transplant. A full-thickness transplant that involves the removal of the central two thirds of the affected cornea. The area is then replaced with donor tissue that is held in place by sutures (Cornea Research Foundation of America, n.d., para 1).
5. Difficult family. Difficult families are those that present challenges to coordinators in granting permission for eye donation of a deceased family member.
6. Eye bank. "An eye bank is a non-profit organization that obtains, medically evaluates and distributes eyes donated by caring individuals for use in corneal transplantation, research, and education" (EBAA, n.d.-b, para. 21)

7. Next of kin. Closest living relative to the decedent. The State of Florida has determined a hierarchal list as to who is considered the legal next of kin. The hierarchy is as follows: (a) the spouse of the decedent, (b) an adult son or daughter of the decedent, (c) either parent of the decedent, (d) an adult brother or sister of the decedent, (e) an adult grandchild of the decedent, (f) a grandparent of the decedent, (g) a close personal friend, as defined in § 765.101, (h) a guardian of the person of the decedent at the time of his or her death, or (i) a representative ad litem appointed by a court of competent jurisdiction upon a petition heard ex parte filed by any person, who shall ascertain that no person of higher priority exists who objects to the gift of all or any part of the decedent's body and that no evidence exists of the decedent's having made a communication expressing a desire that his or her body or body parts not be donated upon death.

## Summary

The investigator explored the lived experiences of eye bank coordinators when approaching families to donate eyes of their loved one. The specific problem was that the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent are unknown. The purpose of this phenomenological study was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. To address the problem and achieve the purpose of this phenomenological study, the overarching research question was the following: What are the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families? The information gained from this research can be used to develop a training program and ease the concerns of the coordinators when dealing with difficult families.

Developing an effective training program has an opportunity to increase the number of donors in South Florida and increase the number of corneal transplants performed in the area.  In Chapter 2, the discussion will be about existing literature that is relevant to establishing the existence of the gap and the worthiness of addressing the problem identified in Chapter 1.  Generally, the themes to be discussion in Chapter 2 will cover the topic of experiences of eye bank coordinators when requesting permission for eye donation from bereaved families.

# Chapter 2: Literature Review

## Introduction

Health care professionals can influence families with end-of-life decisions, particularly the decision to donate their loved ones' organs for transplantation. Physicians, nurses, respiratory therapists, and medical and nursing students are not provided information regarding organ donation during their training and cannot knowledgeable speak to families regarding donation (Ingram et al., 2002; Thornton, Curtis, & Allen., 2010; Whisenant & Woodring, 2012). Researchers have shown that the attitudes of health care professionals towards organ donation can influence a family's decision to donate organs (Henry & Rossen, 2013; Ingram et al., 2002; Whisenant & Woodring, 2012). First-person authorization can relieve families from making the decision to donate eyes upon a loved one's demise. More people are encouraged to join the donor registry to make their final wishes known. The general problem is that it is difficult to access the family's progress in the grieving process when calling for eye donation (Hogan et al., 2013; Rodrigue et al., 2003). The specific problem is that the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent are unknown. The purpose of this phenomenological dissertation study was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. The investigator focused on exploring the lived experience of eye bank coordinators when approaching families for eye donation. The theory of planned behavior and self-perception were used to guide the investigator in exploring positive and negative experiences of eye bank coordinators when requesting permission for eye donation from bereaved families.

In this chapter, the focus of the literature review was the discussion of themes that were relevant to the problem of the study. The contents of the chapter include the legislation related to eye donation and how laws have helped eye banks in obtaining consent. Topics, such as the history of eye banking, laws related to eye banking, consent acquisition process, factors influencing donation decisions, family experiences, and training or education about donation were also included as the themes for the literature review. Finally, first-person authorization was discussed as one of the most effective means of ensuring organ or eye donation. In the end, a discussion of the contribution and summary of the review was provided.

Based on the different components or themes in the problem and purpose of the study, a comprehensive literature review was conducted. The purpose of the review was to explore existing evidence in the academic field in relation to the topic of successful acquisition of consent for eye donation for bereaved families of donors. Therefore, the investigator conducted an electronic search of existing literature from different electronic databases and Web sites of relevant organizations. The electronic databases that were accessed included EBSCOHost, ERIC, JSTOR, ProQuest, PsychArticles, ScienceDirect, and Google Scholar.

The key words used for performing the different searches included eye donation, consent, family, coordination, self-perception, and planned behavior. From these key terms in this literature review, the investigator targeted a strategic approach to the evidentiary search and developed a concatenated search of terms to target the search effort. Resulting search strings included “eye donation + coordination,” “eye donation + consent + coordinator + family,” “eye donation + family,” “eye donation + coordinator + self-perception,” “eye donation + coordinator + planned behavior,” and “eye donation + coordinator + planned behavior +family + consent.” Furthermore, as the investigator encountered relevant articles using these search key terms, secondary or tertiary searches were also incorporated by using the relevant terms and references contained in the articles obtained. Moreover, the academic documents included in the literature review were an academic journal or part of the proceedings from respectable associations and organizations and works originally published in English to avoid potential translation errors.

## Theoretical Framework

Theoretical frameworks were used to guide the research and the research questions. This research was guided by two theories that were used to help understand the lived the experiences of eye bank coordinators. These research theories were the theory of planned behavior and self-perception theory.

**Theory of planned behavior**. The theory of planned behavior was used to guide the research. The theory of planned behavior is often used as a model to predict human social behavior (Ajzen, 2011; Ajzen, 1991; McEachan et al., 2011). The theory of planned behavior presents that behavior is driven by an individual’s behavioral intention and perceived behavioral control (Ajzen, 2011; Ajzen, 1991; McEachan et al., 2011). Perceived behavioral control refers to people’s perception of the ease or difficulty of performing the behavior of interest (Ajzen, 1991). According to Ajzen (1991), perceived behavior varies across situations and actions. For the dissertation study, the perceived behavioral control for eye bank donation refers to the perception of the coordinator about the extent of control of the situation when communicating with bereaved families. This theory was related to the dissertation study as it guided the investigator in analyzing the decision and manner of communication of the eye bank coordinator towards the bereaved family. Using the three components of the theory of planned behavior, attitude toward the behavior, subjective norm, and perceived behavioral controls, the investigator could better understand the experiences of coordinators when acquiring donation consent from bereaved families (Ajzen, 1991).

Critics have scrutinized the theory of planned behavior over the past several decades. Some of the criticisms included (a) the theory is too rational, (b) the theory neglects affect and emotions, and (c) sufficiency assumption (Ajzen, 2011). The thought that the theory is too rational means that theory does not take into account cognitive and affective processes that are known to bias human judgment and behavior. Ajzen (2011) explained that while the theory has emphasis on the controlled aspects of human information processing and decision making, the primary concern is with behaviors that are "goal-directed and steered by conscious self-regulatory processes" (p. 1116). Also, there is no assumption in the theory of planned behavior that behavioral, normative, and control beliefs are formed in a rational, unbiased manner or that they accurately represent reality (Ajzen, 2011).

Critics claimed that the theory does not include concepts of emotion and affect. The concern is that the theory of planned behavior does not include affect and emotions and is in part a mistaken perception that the theory presents a "rational actor who is unaffected by emotions and in part on the standard methodology that is typically used to operationalize the theory's construct" (Ajzen, 2011, p. 1116). Affect and emotions are factored in theory of planned behavior as these concepts serve as background factors in which behavioral, normative and/or control beliefs are influenced (Ajzen, 2011). For example, mood can have a systematic effect on belief strength and evaluations (Ajzen, 2011). Thus, affective states can select behavioral, normative, and controlled beliefs that are readily available accessible in memory (Ajzen, 2011).

Critics have also raised the issue of sufficiency assumption. Ajzen (2011) stated, critics have stated that the theory of planned behavior does not sufficiently explain people's intentions and actions. According to the theory of planned behavior, one should be able to predict performance of a behavior from intentions to perform the behavior and from perceived behavior control (Ajzen, 2011). Intentions should also be predictable from attitude towards the behavior, subjective norm, and perceived behavior control (Ajzen, 2011). Ajzen (2011) maintained that the theory of planned behavior does indeed permit quite accurate prediction of intentions and behavior, albeit coming close to theoretical limits.

McEachan et al. (2011) conducted a meta-analysis and found that theory of planned behavior provided strong predications of intention and behavior across a range of health behaviors. McEachan et al. (2011) indicated that theory of planned behavior could explain 19.3% of the variance in behavior and analysis and indicated that it could explain 44.3% of the variance in intention across studies (p. 125). This finding is slightly lower when compared with previous meta-analytical reviews in which 27% and 36% of the variance in behavior could be explained by intention and perceived behavioral control (McEachan et al., 2011). With this meta-analysis, there is clear support for the theory (Ajzen, 2011). McEachan et al. (2011) demonstrated that the theory of planned behavior is an adequate theory for predicting behaviors.

The theory of planned behavior has been used in several studies to predict human behavior. Since the theory's introduction in 1985, it has become the most frequently cited and influential models for the prediction of human social behavior. According to Ajzen (2011), with a Google Scholar search, there were 4,550 citations that used theory of planned behavior (p. 1113). Theory of planned behavior was used to predict the behaviors that will increase college students' support of organ donation and organ donor registry (Peltier, D'Alessandro, Dahl, & Feeley, 2012). From the theory of planned behavior, Peltier et al. (2012) examined how "various antecedents influence intent and behavior, assess the role of social acceptance and norms, and measure the strength between intent and registration" (p. 324). Based on this theory, Peltier et al (2012) examined five factors that have been linked to support for organ donation and/or organ donor registration. These factors were (a) awareness of organ donation, (b) whether college students acknowledge a need for organ donation, (c) college students' perceptions of the benefits of organ donation, (d) college students' and their networks' willingness to provide social support for organ donation, and (e) concerns about organ donation held by college students.

The theory of planned behavior has also been used to assess and improve attitudes and knowledge toward organ donation among nursing students. Whisenant and Woodring (2012) used the theory of planned behavior as a framework to create an educational intervention strategy designed to affect nursing students' knowledge and attitude toward organ donation and transplantation. Using the educational intervention, Whisenant and Woodring (2012) created and implemented each of the predisposing, enabling, and reinforcing factors.

In the field of eye donation, the theory of planned behavior was used in understanding the phenomenon of eye donation based on factors that are external to the coordinator. The investigator assessed or analyzed the behavior of coordinators based on the perception towards the environment, the situation, and the attitude of the bereaved family. The investigator used the three components of the theory of planned behavior: attitude toward the behavior, subjective norm, and perceived behavioral controls to better understand the experiences of coordinators when acquiring donation consent from bereaved families (Ajzen, 1991). However, for a complete and more comprehensive exploration of the phenomenon from the point of view of the coordinator, internal factors must also be considered. Therefore, the theory of self-perception was also a part of the foundational theories of the study.

**Self-perception theory**. The focus of self-perception theory is on the individual and the internal aspects of perception within the eye bank coordinator. Self-perception theory presents that individuals come to know their own attitudes and other internal states by inferring observations of their own behaviors and circumstances in which they occur (Bem & McConnell, 1970; Bem, 1972). Bem stated that individuals become aware of their own attitudes, emotions, and other internal states partially through the process of inferring from observations of oneself and of others around them (Bem, 1972; Bem & McConnell, 1970). Moreover, the theory presents that partial identity exists between self and interpersonal perception of the extent to which internal cues are weak, ambiguous, or uninterpretable (Bem, 1972; Bem & McConnell, 1970).

The theory includes the exploration of the individual as observer. The individual is functionally in the same position as an outside observer (Bem & McConnell, 1970). The observer, who must necessarily rely upon those same external cures, infers the individual's inner states (Bem, 1972; Bem & McConnell, 1970). This theory presents an alternative explanation for the phenomena of cognitive dissonance theory. This argument is demonstrated with the case of the forced-compliance experiment in which individuals write counter-attitudinal essays for varying amounts of money. The individuals who participated in the study wrote essays for little or no compensation "expressed post-manipulation attitudes which reflect agreement with the position taken in the essays, whereas the final attitudes of individuals who write essays for large compensations are not significantly different from those expressed by control subjects who did not write essays" (Bem & McConnell, 1970, p. 23).

Related studies have been conducted using self-perception theory as the framework. Festinger and Carlsmith (Bem, 1972) recruited 60 undergraduate students and randomly assigned them to three experimental conditions. One group was paid $1 to perform long repetitive tasks, the second group was paid $20 to perform the same tasks, and the third group (control group) was not compensated to perform the tasks. Also, one hypothetical observer in each group was paid the same as the participants of the groups to tell a waiting student that the tasks were enjoyable and interesting. Once the experiment was completed, the all of the students indicated they enjoyed performing the tasks. The $1 group evaluated the tasks as significantly more enjoyable than the subjects who were paid $20. Also, the group that was not compensated did not express attitudes significantly different from the group that was paid $20.

The self-perception theory presents these results again by considering the viewpoint of the outside observer who hears the individual making favorable statements about the tasks to a fellow student, who further knows how much the student was paid to do so. The hypothetical observer was asked to state the actual attitude of the individual he/she has heard. If the observer had seen the individual making such statements for little compensation ($1), the observer can rule out financial incentive as a motivating factor and can infer something about the individual's attitudes (Bem, 1972). Also, the observer can conclude that the individual holds an attitude consistent with the view that was expressed in the behavior (Bem, 1972). However, if an observer sees an individual making such statements for the group that was compensated $20, he/she can infer that little or nothing about the attitudes because the incentive was sufficient to evoke the behavior regardless of the individual's personal views (Bem, 1972).

Through self-perception, an individual will use his or her personal behavior as a source of evidence for his or her beliefs and attitudes to the extent that the contingencies of reinforcement for engaging in the behavior are made subtler or less discriminable. The self-perception theory was used to interpret results by considering the viewpoint of the observer or the coordinator in relation to acquiring the consent of the family members. If the coordinator sees the family members reacting unfavorably towards donation and are difficult to deal with, then the coordinator will react appropriately by changing personal attitudes and behavior to match the requirements of the family members. On the other hand, if the coordinator sees the family members as more welcoming and open to donation, then the coordinator will also react appropriately to make consent acquisition easier.

## History of Eye Banking

The eye bank is an organization that caters to patients in need of corneal transplant. The purpose of an eye bank is to procure, store, and distribute eye tissue (Farge, 1989, p. 260; Paton, 1956). The corneal tissue is used to provide sight to those that are blind due to a corneal disease or corneal trauma.

Before the eye bank was established, Dr. R. Townley Paton would drive to Sing Sing penitentiary. The purpose of this journey was to approach prisoners who were to be executed for permission to harvest their corneas upon their death to help those with corneal blindness. During this drive to his New York home, the idea that living people could agree to eye donation upon their death and next of kin could be approached by hospital staff to obtain consent to harvest the eyes of their loved one after their death (Farge, 1989).

The eye bank has roots in New York City. The first eye bank was founded in 1944 under the direction of Dr. R. Townley Paton (Farge, 1989). The facility was named the Eye Bank for Sight Restoration (Farge, 1989; Paton, 1956; Payne, 1980). Gradually, this eye bank began to expand and had branch offices in Boston, Philadelphia, Winston-Salem, New Orleans, Chicago, San Francisco, and Los Angeles (Paton, 1956; Payne, 1980). As the eye bank grew, they began to procure from several different sources. These sources included hospitals and medical examiner offices (Paton, 1956; Payne, 1980).

Initially, transplantation needed to occur 24 to 72 hours after preservation. When tissue became available, patients were called and immediately and went to the hospital for surgery. The introduction of new storage media allowed transplantation to occur later. Tissue preserved in the new media could be used up to 10 days after preservation, allowing surgeons to schedule patients for surgery. Other advances included using a specular microscope to evaluate the tissue and improve tissue quality (Chu, 2000; Doughman, 1988; Farge, 1989; Payne, 1980; Payton, 1956).

With these new developments came the establishment of the Eye Bank Association of America in 1961. The EBAA was responsible for developing medical standards for eye banks, including medical screening of donors, testing, evaluating of tissue, quality control of the eye bank laboratory, and standardizing procurement technique (Chu, 2000; Doughman, 1988; Payne, 1980). In 1980, the EBAA adopted the set of medical standards set by the medical community. The major headings that the committee addresses are (a) statement of purpose, (b) outline of the organization of an eye bank, (c) medical directors and their qualifications, (d) eye bank technicians and their qualifications and training, (e) laboratory facilities, (f) acceptability of donor tissue, (g) record keeping of donor tissue, (h) enucleation procedures, (i) inspection of donor tissue, (j) inspection of eye banks, and (k) certification and recertification of eye banks and eye bank technicians (Chu, 2000).

Aside from the EBAA, U.S. government has also implemented laws in relation to eye donation. These laws make eye donation a part of the objectives of the government as part of its health programs. Understanding these laws will help in comprehending the roles of an eye bank coordinator within the phenomenon of consent acquisition for donation.

## Legislation Related to Eye Donation

Obtaining consent for eye donation can be accomplished four different ways under different existing laws. The U.S. government has passed several laws for eye banks to obtain eye tissue to help those who suffer from corneal blindness. These legislative policies include the Uniform Anatomical Gift Act, Medical Examiner/Justice of the Peace Law, Routine Inquiry or Required Request Law and Drivers' License Laws.

The Uniform Anatomical Gift Act became effective in 1970. This act is used for people to designate themselves as an eye donor upon their death. The donor signs a form of consent and turns the form over to the nearest next of kin (NOK) or someone who is making funeral arrangements. Upon the donor's death, the form is given to the funeral home and the enucleation is arranged with the local eye bank. This form is a legal authorization for eye enucleation. With this law, NOK are able to donate tissues of their loved one by signing a consent form with the signature of a witness (Farge, 1989; Farge et al., 1994; Paton, 1956). The Uniform Anatomical Gift Act helped increase eye donors to 215 ± 87 per year from 72 ± 38 per year for the Lions Eye Bank of Texas (Farge et al., 1994).

Another law is the Medical Examiner/Justice of the Peace Law, which was first passed in Maryland in 1975. Since 1975, the law has been passed in several other states; presumed consent is endorsed with this law. With this law, the medical examiner or justice of the peace is permitted to remove corneas from bodies that are under their jurisdiction. This consent is obtained from the medical examiner or justice of the peace without the consent of the legal NOK unless there is a known objection to donation from the potential donor or the family (Farge et al., 1994; Farge, 1989). For the Lions Eye Bank of Texas, this law increased donors to 1,329 ± 562 per year (Farge et al., 1994). In 1977, when the law was enacted in the State of Florida, corneal transplants increased from 500 in 1975 to 3,000 in 1984 (Orentlicher, 2009).

Beginning in 1982, many states passed the Routine Inquiry or Required Request Laws. These laws required hospital personnel to notify the NOK of the option to donate tissues and organs from their loved one. In section 1938 of these laws, each hospital participating in Medicare reimbursements must offer NOK a chance to donate (Farge, 1989). For the Lions Eye Bank of Texas, this law increased eye donation to an average of 1,958 ± 33 donors a year (Farge et al., 1994).

The final law related to eye donation is the Driver's Licenses Law, which was adopted in several states. With this law, a driver's license can be used to serve as an anatomical gift card. Signing one's driver's license is a legally acceptable expression of one's intention or consent to become a donor upon his or her death (Farge, 1989).

Based on the different laws in the United States about organ and eye donation, citizens are given multiple opportunities to become donors, especially upon death. However, the problem of encouraging family members to consent to donation of organs, specifically the eyes, is still present within the society. The main persons involved in encouraging families to give their consent for organ donation are the coordinators. By understanding the consent acquisition process, readers can become more aware of the overall experience of donation coordinators.

## Consent Acquisition

The standard for obtaining consent for eye and tissue donation is to call the next of kin hours after the death of their loved has occurred. Trained staff members typically approach the next of kin for permission to obtain eye or tissue donation over the telephone (Verble et al., 2013). There are many factors that can hinder donation when approaching next of kin on the phone. Timing, acceptance of the death, and the grieving process are all factors that can influence the next of kin's decision to donate their loved one's eyes or tissue. The eye bank coordinators are tasked with making the phone and obtaining permission for the donation to take place. The main reason why eye and tissue approaches are conducted over the phone rather than in person like organ approaches is because there are far more suitable donors for eye and tissue than there are for solid organ (Siminoff & Traino, 2013), therefore, logistically making telephone approaches more feasible.

When an eye bank coordinator or tissue requestor is approaching next of kin for consent, it is crucial that the family member is given all the necessary information to make an informed decision. Siminoff and Traino (2013) identified which information is given to the family at the time of approaching for consent. Siminoff and Traino used tissue banks across the United States. Tissue banks mainly ask permission for skin, corneas, ligaments, cartilage, heart valves, and bone (Traino & Siminoff, 2013). Siminoff and Traino (2013) found that in 92.4% of the discussions, the name of the tissue bank was included in the conversation with the next of kin. Among other informational items that were found in one half to two thirds of the discussions were the need for testing to determine medical suitability (65.1%), disclosure of the families' right not to donate (62.4%), a general discussion of the procurement process (60.9%), general comments about funeral arrangements (57.1%), the ability to have an open casket funeral (54.4%), and the timeframe for making a donation decision (54.8%; Traino & Siminoff, 2013). They also found in less than half of the conversations, information pertaining to processing (26.0%), storage (23.6%), and distribution (31.8%) of the donated tissue and the possibility of potential involvement of for-profit and not-for-profit companies using the tissue (26.5%), the potential use of the tissue being used for cosmetic or reconstructive purposes (29.1%), and the families right to place restrictions on the use of the donated tissue were discussed (37.6%; Traino

& Siminoff, 2013). Discussion regarding the potential use of the tissue in a foreign country or the families' right to withdraw consent was discussed.

In the United States, the premise of organ and tissue donation is based on the bioethical principle of autonomy. Autonomy is when an individual is capable of and has a right to self-determination or "self-rule" (Traino & Siminoff, 2013). The number of people who claim to want to become a donor upon their death it is estimated that only 40% of the population are enrolled on the state registry and only 70% have communicated their desire to next-of-kin (Traino & Siminoff, 2013). The researchers concluded that tissue requestors are in need of constant training in providing informed consent to families who are presented with the option of tissue donation. Tissue requestor should strive to provide the same quality and quantity of information to all families regardless of whether they donate or refuse (Traino & Siminoff, 2013).

In studies conducted in both France and Spain, telephone consents were found to be effective and efficient; however, calling families after the death of their loved one does have its obstacles. In France, Gain et al. (2002) recruited a total of 334 families for their study. Of the 334 families, 142 were contacted by face-to-face interview and 192 were contacted by telephone. The time between death and the either face-to-face or telephone interview ranged from 2 to 18 hours. During the face-to-face interview, 81.6% of families gave consent while with of telephone approaches, 55.2% of families granted consent for eye donation ($P < .001$). Also, during the telephone calls, 30% gave their response at once, and 70% of cases requested more time to make a decision. Three people never called the coordinator back and 132 people called back within 3 hours (Gain et al., 2002). Finally, five families said they were shocked as were five families in the face-to-face interview. It is also worth noting that 24.1% of families could not be reached within the 18-hour deadline either because there was no phone number listed at the hospital or that the family did not answer the phone, despite the repeated calls that were made (Gain et al., 2002). The researchers concluded that despite the lower percentage of consented donors during phone interviews, 55.2% consent rate was still high enough to consider using the telephone as efficient (Gain et al., 2002).

Other researchers focused on the consent acquisition process with families of potential donors. Rodriguez-Villar et al. (2007) reported similar findings after analyzing 770 potential donors. Of the 770,503 interviews were conducted in person, 222 interviews were held on the telephone, and 45 families could not be reached. The rate of consent for donation among the in-person interviews was 59% compared with 52% of consents when the interview was conducted over the phone. Interestingly, the 106 families who refused consent in person totaled a loss of 129 cornea donors and 79 cornea donors through telephone interviews (Rodriguez-Villar et al., 2007).

Some researchers showed that the time between the death of the potential donor and the time of the approach for consent may have an effect on consent refusal. Niles and Mattice (1996) stated that although there are few studies that focus on the timing of the consent approach, it is important that the family has time to accept the death before someone speaks to them regarding donation. Niles and Mattice (1996) analyzed 127 cases that were suitable for organ donation. Of these 127 families, 56% resulted in consent for donation, and 44% refused donation. Hospital staff was encouraged to wait to approach for consent until after the family was notified of the death. However, some eager staff members spoke to the family before brain death was determined. It was found that despite the timing, consent was granted and that there was no difference between waiting and approaching before the death occurred.

Other scholars explored the consent process and the reasons for families to decline to the request for donation. Verble et al. (2013) analyzed 755 of these families, 300 gave consent for eye donation, and 455 refused. Reasons for refusing donation among the 455 families were as follows: 26.1% did not want to go against the expressed wish of the decedent, 13.4% did not know the wishes of the decedent and did not want to say yes, 8.3% wanted the body buried whole, 7.7% hung up, 7.7% did not call back, 7.2% felt the potential donor was too old or unhealthy to donate, 6.8% said that donation was against their religion or culture, and 6.6% did not give a specific concern (Verble et al., 2013). Also, of the 755 potential donors, 99 were registered donors, and of those 99, 88 families honored the wishes of their loved ones, and 11 families refused to donate, despite the decision made by the decedent. Reasons for not donating among the 11 families were as follows: felt that the decedent had been through enough; feared mutilation, disfigurement, or cutting; wanted the body either buried or cremated whole; the decedent was too old or unhealthy; expressed real or projected family disunity; the decedent expressed the contrary wish, the decedent would not have made a donation; concerned about how the body would look for viewing; and did not want the donation to go to research or be wasted (Verble et al., 2013).

Based on the different studies about consent acquisition, the role of coordinators is indeed complex, especially when dealing with a grieving family. In some cases, these family members have different perceptions of the manner by which coordinators approach them and communicate with them (Rodriguez-Villar et al., 2007; Verble et al., 2013). Other families have concerns with the implication of organ or eye donation to the remains of their deceased loved ones (Verble et al., 2013). Another aspect that makes the process complicated and more difficult to handle is the manner of communication. Most eye donation consent acquisitions occur through telephone conversations (Verble et al., 2013). Because of the lack of personal communication and the importance of timing in the context of successful consent acquisition for eye donation, coordinators must be aware of the different factors that influence donation among families. Knowing the factors that either hinder or promote donation consent are helpful for coordinators to generate a strategy for improving likelihood of success of consent requests.

## Factors Influencing Families' Donation Decision

Family members play a crucial role when deciding if their recently deceased loved one will be an organ, eye, or tissue donor. Several researchers have suggested that families who know the wishes of the deceased prior to death are more likely to donate organs, eyes, and tissues upon their loved one's death. The main reasons for allowing or hindering donation among family members include (a) following loved one's wishes, (b) request from coordinator rather than hospital staff, (c) a family member's proposal, and (d) coordinator's attitude.

**Following loved one's wishes**. A family's decision to donate or not to donate is dependent upon their knowledge of the wishes of the deceased family members. Rodrigue, Cornell, and Howard (2006) found that families that knew the wishes of their loved ones were more willing to follow through with their wishes. Donor participants were asked why they decided to donate. The families mentioned that following the wishes of their loved one whether perceived or actual (34.8%) is a major determinant of the decision to donate or not. If the perceived or actual wish of the deceased is to donate his or her eye upon death, then the family will most likely oblige. Similarly, if the perceived or actual wish of the deceased is not to donate his or her eye upon death, then the family members will most likely decline the request from an eye bank coordinator.

Families of decedents who knew the deceased persons wishes were more likely to oblige by their wishes and carry out those wishes. Siminoff and Lawrence (2002) interviewed 360 families; 171 families knew the wishes of their loved one, and 189 families did not know the wishes of their loved one. They demonstrated that families who knew that their loved one did not want to donate refused to donate when asked (95.55%), whereas 10.24% of those who did not know of their loved one's wishes to donate tissues refused to donate (Siminoff & Lawrence, 2002). When families did not know the wishes of their loved one, they were more likely to refuse to donate (54.50% vs. 45.50%). Finally, those who knew the patient had registered to become a donor were more likely to donate (89.19%) than those who knew they were not registered or did not know (47.55%; Siminoff & Lawrence, 2002).

Nondonor participants were asked why they preferred not to donate their loved ones' tissues, and their responses were (a) 32.7% believed they were following the actual or perceived wishes of their loved one, (b) 27.9% stated negative beliefs or misunderstandings about donation, (c) 15.5% were concerned with pain and suffering, and (d) 14.5% had negative perceptions of the request/donation process (Rodrigue et al., 2003). Cleiren and Van Zoelen examined the effects of death on family members of three groups of bereaved family members. The groups were organ donation consent, organ donation refusal, and family members whose loved one passed away from comparable causes of death; however, no request was made for donation. There was a total of 95 bereaved families that participated in the study: 36 consented to organ donation, 23 refused donating an organ, and 36 families were not approached for organ donation.

**Source of proposal or request to donate**. The person who proposed or requested donation is highly influential to the decision of family members. Rodrigue et al. (2006) also found that 72.2% families were more willing to donate when an organ procurement coordinator made the formal donation request, 74% if a family member, or 34.2% when the hospital staff (physician, nurse, social worker, or clergy/chaplain) first mentioned donation.

**Attitude of coordinators**. The perceived attitude of coordinators is an influential factor to the decision of family members. Rodrigue et al. (2006) found that if the family of the deceased perceived the requestor as more sensitive (3.5 ± 0.6 vs. 2.8 ± 0.9) and compassionate, they were more likely to agree to donate. When the requestor was viewed as compassionate, donation occurred at 67.4%, somewhat compassionate 29.9%, and not compassionate at all 17.5% of the time (Rodrigue et al., 2006). Moreover, Rodrigue et al. found that most of their study participants (81.2%) felt that the requestor was caring and compassionate, they were not pressured into making a decision to donate (92.1%), and they were given enough time to make a decision (72%). Whereas, 92.1% of donor families felt that the requestor was more compassionate and caring than the 70.2% of nondonor families (Rodrigue et al., 2003). They also found a significantly higher number of nondonor participants felt they were pressured to donate (6.3%) compared with 1.6% of donor families (Rodrigue et al., 2003).

**Perception of disfigurement**. Common factors that may influence families not to donate are disfigurement, beauty, and identity (Hermann, Pagnussato, Franke, & Oliveira, 2014; Lawlor & Kerridge, 2011, 2013; Lawlor, Kerridge, Ankeny, Dobbins, & Billson, 2010). Participants in the study stated that when considering organ donation and eye donation, they distinguished that organs are not visible, and therefore, there was no discomfort with organs being removed. Eyes, however, are visible, and families were able to perceive their absence. This physical alteration was a point of distress for families. Eyes were also a symbolic component of disfigurement manifested as concerns about the consequences of the perception of disfigurement or a more tangible feeling that the essence of the person is in some way altered by physically disfiguring the body (Lawlor & Kerridge, 2013). When families were surveyed regarding their willingness to donate corneas, concerns for disfigurement were made by 47% (Lawlor et al., 2010). They also compared disfigurement for the removal of organs with cornea and found that skin ($p < .0001$) and bone ($p < .0001$ are significantly more disfiguring than corneas. Kidneys, however, ($p = .0001$) and hearts ($p = .0003$) were significantly less than disfiguring than corneas (Lawlor et al., 2010). Hermann et al. (2014) found that there are negative feelings towards cornea donation due to the donor's appearance after the tissue is removed (1670). With the fear of disfigurement and loss of physical integrity of the deceased, the family's view of donation is considered as mutilation rather than a surgical procedure (Hermann et al., 2014).

Identity was also a reason people were not willing to donate eyes when asked. Eyes were associated with the decedent's identity. The face enables recognition in a person, and the eyes are a distinctive feature of the face. The eyes convey expression, mediate social interaction, and are the site of sentience (Lawlor & Kerrige, 2013).

To properly address the concerns of these families and increase chances of success of donation requests, the coordinators must be aware of the factors that families consider when deciding to agree with the donation or not. However, aside from knowing these factors, the coordinator must also understand the experiences and feelings of these grieving families. Understanding the family's situation can help the coordinator to become more effective in approaching them and gaining their trust to allow the donation to take place.

## Family Experiences

Families have several reasons why they decide to donate organs, eyes, and tissues upon the death of a loved one. Researchers have explored these reasons and the meaning of the donation of organs, eyes, and tissue to families. Some families find solace and comfort through donating their loved ones' organs, and for others, donating does not have any impact on their grieving process (Beard, Ireland, Davis, & Barr, 2002; Manuel, Solberg, & MacDonald, 2010). Manuel et al. (2010) found that there are five themes surrounding the experiences of families regarding organ donation: (a) the struggle to acknowledge the death, (b) the need for a positive outcome, (c) the creation of a living memory, (d) buying time, and (e) the significance of support networks in the organ donation decision (p. 231). Families described struggle as feelings of shock, inability to process the information provided, and disbelief in the validity of the diagnosis of brain death (Manuel et al., 2010).

In order for the families to restore their sense of peace, they wanted something positive to come out of the death of their loved one. The efforts made by the families to restore peace are helping others live, improving the recipient's quality of life, fulfilling the wishes of the deceased, and creating a living memory of their loved one (Manuel et al., 2010, p. 233). Similarly, Hogan, Coolican, and Schmidt (2014) attempted to learn the from NOK or family decision makers how they found meaning in grieving the sudden death of a loved one and make meaning from donating their loved one's tissue. The questions asked were "If you could ask or tell your dead family members something, what would it be?" and "What does donating tissue to others have for you?" (Hogan et al., 2014, pp. 183-184). They found four concepts when analyzing the question, "If you could ask or tell your dead family members something, what would it be?" These concepts were (a) feeling empty, (b) missing and loving, (c) being grateful, and (d) having regrets (Hogan et al., 2014, p. 183). Analysis of Question 2 included "What does donating tissue to others have for you?" and showed five concepts that were similar to the findings of Manuel et al. (2010). These concepts are (a) fulfilling their family member's wishes, (b) doing the right thing, (c) believing something good came from the death, (d) helping others, and (e) living on through others (Hogan et al., 2014). This study helps provide an understanding to meaning of donating tissue to grieving family members. Hogan et al. (2014) also confirmed that family members want to honor the wishes of their loved ones and want to do the right thing.

To access the impact of approaches made to families who donated tissues of loved ones and to examine the consent process at the Donor Tissue Bank of Victoria, Beard et al. sent questionnaires to 339 families. Of the 339 families surveyed, 58% of the questionnaires were completed. Families were asked whether the donation had an effect on them or their family or if they felt comfort from the donating. Some families (6.6%) said they needed to know the outcome of the donation, some felt that the information would allow some comfort, and some found comfort in knowing that they tried to help someone. Other families (3.5%) said they felt comfort in knowing they were able to fulfill their loved ones wishes to become a donor. Finally, 10.1% of families said they felt comfort from doing the right thing, making an impact on someone's life, and knowing that their loved one did not die in vain (Beard et al., 2002). Areas in which some families felt needed improvement were (a) the need to know the outcome of the donation, (b) the need for education about tissue donation to minimize shock, (c) how too much detailed information was given, and (d) rephrasing of harsh questions (Beard et al., 2002). As far as the approach process, 85.7% of families had positive comments. Families felt that the approaches were considerate, sensitive, compassionate, professional, sympathetic, down to earth, practical, caring, and factual (Beard et al., 2002). The Donor Tissue Bank of Victoria will review their practices and procedures for improvement for future donor families (Beard et al., 2002).

Families indicated both positive and negative experiences when asked about the donation process. Strouder et al. (2009) surveyed 170 donor families about their experience with the organ donation process. Eighty four percent of the respondents indicated that the most helpful way in dealing with their grief was family support, followed by support from friends at 74%, and religious and cultural beliefs at 37% (Strouder et al., 2009). The comments on the nature of the negative comments were (a) hospital charges, unrelated to organ donation; (b) delay in time to transfer the patient to operating room; (c) lack of support after donation; (d) consent process too long; (e) desire for more family privacy; and (f) in all phases of the process, needed more time (Strouder et al., 2009). The strongest expressions of feeling were (a) very ecstatic; (b) incredible kindness; (c) extremely professional; (d) very happy; (e) great feeling; (f) totally supportive; (g) exceptionally patient; (h) unexpectedly comforting; (i) most frustrating, billing issue; and (k) tremendous anguish, delay to operating room (Strouder et al., 2009). Factors that may help "profile" a family as most likely to say yes are (a) that they understand that their loved one is dead, (b) they have been given enough information about donation, (c) they felt that the approach was made at an appropriate time, (d) they were treated respectfully at the hospital, (e) they felt that their loved one received good care, and (6) they had previously discussed donation with the donor (Strouder et al., 2009). These factors are much easier to identify when the organ procurement organization representative is at the hospital and can assess the family's reactions.

Overall, each family grieves in its own way and at its own pace when a loved one is lost. The grief of families is also something that coordinators must consider. Hogan et al. (2014) were able to demonstrate that bereaved family members follow the normal pattern of grief, which may help alleviate concerns regarding approaching for tissue donation too close to the time the family was notified of the death. Tissue donor family members believed that being able to donate tissue or organs gave them comfort during their grief (Hogan et al., 2014). Understanding how donor families cope with their loss and help others during this time through organ, eye, and tissue donation could help donor coordinators increase consents. Little is known about how approaching families during this devastating time in their lives affects their grieving process. It is unknown whether the donation gives the family solace during this time or if it causes additional emotional stress at this already difficult time. Therefore, knowing how to communicate properly is an important factor to the success of coordinators when requesting for donation consent.

## Verbal and Nonverbal Communication

Verbal and nonverbal communication is an essential form of communication for healthcare providers. Siminoff and Step (2011) described a computerized program to facilitate the analysis of health care conversations. Communication is fundamental to advancing the understanding of how people access, obtain, and use health care services. Nonverbal and verbal communication can convey multiple layers of messages (Siminoff & Step, 2011). Confirmation is defined as the "metacommunicative process through which a person's self-definitions are accepted, acknowledge, or endorsed by others," and disconfirmation is the "metacommunicative process by which a person's self-definitions are denied, avoided or otherwise invalidated" (Siminoff & Step, 2011, p. 4).

A major challenge for eye and tissue coordinators is approaching the families of potential donors over the telephone in order to obtain consent. The coordinator must give the family enough time to grieve and information in a comprehensive and compassionate manner. It is impossible to access the families' body language over the phone, and coordinators must rely heavily on verbal and nonverbal cues. Siminoff, Triano, and Gordon (2011) analyzed audio recordings of consent for 1,016 participants; of the 1,016 participants, 606 consented to tissue donation, and 410 who refused. They hypothesized eight domains that would have an effect on consents, which are (a) decision-maker sociodemographics, (b) tissue-requester sociodemographics, (c) decision-maker tissue donation attitudes, (d) decision-maker communication, (e) tissue-requester communication, (f) relational communication, (g) persuasive communication, and (h) time (Siminoff et al., 2011). Siminoff et al. (2011) found that families who spent more time engaged in conversation about donation were nine times more likely to donate (adjusted odds ratio = 9.10, 95% confidence interval [5.83, 14.19]). Also, "decision makers' sociodemographic characteristics and tissue donation attitudes were positively associated with consent as were the verbal and nonverbal aspects of decision makers' communication" (Siminoff et al., 2011, p. 9).

## Training or Education to Encourage Donation

Formal training for improving knowledge about donation and transplantation is important for coordinators to have the necessary skills to become effective in performing their tasks. Whisenant and Woodring (2012) found that some nursing programs offered courses in transplantation as electives. In an effort to increase knowledge among nursing students, the United Network for Organ Sharing (UNOS) created the Nursing Curriculum Initiative and created a curriculum guide, which provides nursing school with materials to facilitate communication with faculty and experts in the procurement field (Whisenant & Woodring, 2012). Unfortunately, the guide was never adopted as a requirement for nursing schools by any national nursing accreditation body (Whisenant & Woodring, 2012). Whisenant and Woodring (2012) corroborated findings by Ingram et al. (2002), which was increased knowledge among nurses increased the attitudes of nurses positively. To further substantiate the previous two studies, Hoy, Alexander, and Frith (2011) indicated educating nurses affects their attitudes toward organ donation, which may influence families to donate. Hoy et al. (2011) examined the effects of a five-week online transplantation elective course about graduate nursing students. Hoy et al. (2011) conducted a study at the University of Alabama Huntsville and found a significant difference in the respondents' ability to discuss transplantation with friends and family. Nursing students' responses demonstrated significant changes after the five-week online course in the areas of encouragement of organ donation ($p$ = .04), advocacy for transplantation ($p$ = .003), and confidence speaking with communities about organ donation ($p$ = .001; Hoy et al., 2011). Hoy et al. (2011) indicated that pretest scores were strongly positive in personal designation as an organ donor (93%, $n$ = 30) and plans to encourage others to donate organs (90%, $n$ = 30). It is crucial for nurses to be able to discuss donation options with families to improve organ donation rates (Hoy et al., 2011). Despite the need to educate health care professionals, such as nurses, offering transplantation courses as a requirement of the curricula does not seem as though transplantation courses will be implemented.

Zheng et al. (2012) stated that a significant number of American medical schools were unable to provide instruction for implementing different processes on donation, such as consent processes, definitions of brain and cardiac death, and the discussion of organ donation during routine health care visits. The lack of education toward organ donation procedures and information has an effect on the comfort level and unfavorable attitudes toward organ donation, leaving future health care providers unprepared to talk to their patients about organ donation. Zheng et al. (2012) theorized that early experiential learning has increased students' confidence, motivation, and development of intellectual skills in many subjects; organ donation curriculum for medical students may improve health care providers' knowledge of and attitudes toward organ donation. Obtaining consent for organ and tissue donation is optimized when providers themselves have a favorable attitude toward donation; speaking with a physician can be a positive predictor toward donation (Zheng et al., 2012). Students from the University of California, San Francisco, School of Medicine created and implemented an elective for premedical students (Zheng et al., 2012). Students indicated they had an increased knowledge of organ donation and reflected positively on their experiences; however, this knowledge did not lead to an increased score for knowledge of donation (Zheng et al., 2012). Moreover, the studies for positively influencing donation perceptions through education were not focused on the coordinators' job of becoming effective in working with families for consent acquisition. However, the most effective means of ensuring donation from potential sources will be first-hand or first-person authorization.

**Communication of difficult news**. Communicating difficult news to patients and families regarding a loved one is a difficult task for physician. The stress level of the physicians increases when they are in a position to deliver bad news to patients and/or loved ones. Physicians are affected by the stress of these transactions for several hours to days after the conversation occurred (Ptacek, Fries, Eberhardt, & Ptacek, 1999; Ptacek, Ptacek, & Ellison, 2001). Some physicians also reported feeling depressed, and the task of delivering unfavorable news can cause temperament changes and work dissatisfaction (Kumar et al., 2009). Physicians who participated in the studies felt that there was a lack of training in communication of bad news to patients and their families and that it should be incorporated in their training (Baile, Lenzi, Parker, Buckman, & Cohen, 2002; Fallowfield & Jenkins, 2004; Kumar, 2009; Ptacek, Fries, et al., 1999; Ptacek, Ptacek, et al., 2001).

## First-Person Authorization

A first-person authorization is a consent that a living donor gives for permission to donate organs or parts of the eyes upon his or her death. Nationally, donor registration in the United

States is at 40%; 27 states are below the minimum standard rate of less than 50% (Peltier, D'Alessandro, Dahl, & Feeley, 2012). College students have underparticipated in organ donor registration. It is estimated that organ donor registration among college students ranges from the 8th to the 58th percentile with a mean of 23% (Peltier et al., 2012). The goal of Peltier et al. (2012) was to test a framework for college students' decision making in the context of organ donation. They focused on conceptual issues, such as donor education, family discussions, benefits and barriers, and the targeting of other psychosocial issues. Peltier et al. (2012) reviewed the literature and showed five factors that influenced support for organ donation and/or organ donor registration, and they are the following: (a) awareness of organ donation, (b) whether college students acknowledge a need for organ donation, (c) college students' perceptions of the benefits organ donation, (d) college students and their social networks' willingness to provide social support for organ donation, and (e) concerns about donation held by college students. Social support had a direct effect on both donation support and actual registration behavior. They suggested that discussion with family and other social networks played a key role in the formation of attitudes toward organ donation and organ donor registration behavior. Discussion and social expectations reduced fears and concerns to enhance support for organ donation (Peltier et al., 2012).

Efforts are underway to increase the number of persons who have registered to become an organ, eye, or tissue donor. First-person authorization "makes the indication of an adult's intent to donate some or all organs and/or tissue via a driver's license, a donor card, or other documents legally binding" (Traino & Siminoff, 2013, p. 2). Traino and Siminoff (2013) compared the attitudes, knowledge, and behaviors of families of designated donors with individuals whose families did not have documentation of their loved ones' wishes; effectiveness and acceptability of donor designation legislation was also examined. The authors invited nine organ procurement organizations throughout the United States to be a part of this study. The families sampled were divided into three groups: families that authorized donation, declined donation, and families of designated donors. They found that knowledge of loved ones' wishes regarding donation aided the families in their decision making, increased the likelihood of familial authorization and satisfaction with the final donation decision, and did not add additional stress to the already bereaved families (Traino & Siminoff, 2013). The results of the study were as follows: (a) nearly two thirds of the designated donor families were aware of the decedent's decision to register as a posthumous donor (65%); (b) 14% of families who were unaware were not comfortable with the manner in which they were informed of the decedent's donor status; and (c) 12 families stated that this information added to their stress because of lack of family communication, the family's position again organ donation, and the use of life support to maintain the donor for donation purposes (Traino & Siminoff, 2013). Of the families that were unaware of their loved ones' wishes to be a posthumous donor, the decision was vastly accepted; however 17% expressed dissatisfaction of the way in which they were told of their loved ones' decision to be a donor (Traino & Siminoff, 2013).

## Contribution

A gap in the literature was filled with the results of the dissertation study as well as an understanding of the lived experiences of eye bank coordinators before, during, and after calling a family. However, researchers have not assessed the attitudes and beliefs of eye bank coordinators. According to past research, the comfort level of health care professionals regarding eye donation comes through to the family as being uncomfortable and unknowledgeable on the topic. This level of comfort and knowledge may also come through on the phone to families if a coordinator has a bad experience with one family and then may have to make another call immediately after. Exploring these experiences and finding commonality among eye bank coordinators may help a training program that would help eye bank coordinators get through an uncomfortable situation with a family. Using planned behavioral theory and self-perception theory in the concept of obtaining eye donation consent from grieving families will advance the scope of the theories. Moreover, using the two theories helped the investigator in analyzing the experiences of coordinators to become more effective in requesting for the consent of families for eye donation.

## Summary

Eye banking associations and the government have been active in promoting eye donation within the United States. However, succeeding to encourage people to donate the organs, specifically the eyes of a deceased family member, is still persistent within the society. Majority of the responsibility to making sure the donation takes place is placed on the coordinator. However, with the complex process of acquiring consent for eye donation, coordinators must have specific skills and attitude to appropriately approach the grieving family and the knowledge of right timing. There is a gap in literature in terms of addressing the attitudes and beliefs of the eye bank coordinators who speak with the families to approach for consent

This dissertation added knowledge to the current literature regarding lived experiences of eye bank coordinators across the country. Researchers have examined the attitudes and knowledge of nurses, physicians, respiratory therapists, and medical students; however, the researchers have not assessed the attitudes and beliefs of eye bank coordinators. The knowledge gained from this research has created an opportunity to increase eye donation in South Florida.

Increasing the confidence levels of eye bank coordinators has an opportunity to increase the number of families who give consent to eye donation at the time of their loved ones' death, increasing the number of donors who can help those suffering from corneal blindness regain their sight. In Chapter 3, the discussion will be focused on establishing the appropriate methodology and research design to be implemented in order to fulfill the purpose and address the research questions of the study about the experiences of eye bank coordinators when interactive with bereaved families of prospective donors.

# Chapter 3: Methodology

## Introduction

To explore the lived experiences of eye bank coordinators when calling families to obtain consent for eye donation, an interpretive phenomenological analysis was conducted. The eye bank coordinators who participated in the study were from three different eye banks throughout the country. A semi-structured phone interview was performed to gain insight into their experiences when speaking with families. Once the interviews were completed, the data analysis began. Minimal resources were required to conduct this qualitative dissertation study. With this method, the investigator was able to discover the lived experiences of eye bank coordinators before, during, and after making calls to families to obtain consent for eye donation.

To address the problem and achieve the purpose of this phenomenological study, the overarching research question is What are the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families?

The specific research questions are

RQ1. What are the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families?

RQ2. How do the positive and negative lived experience of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families?

### Research Design

This dissertation study was a qualitative study, specifically an interpretative phenomenological analysis (IPA). IPA was appropriate to the study because each of the research questions is concerned with exploring the lived experiences of participants (e.g., eye bank coordinator) and how these participants make sense of their experiences (Callary et al., 2015). Phenomenological research naturally introduces and involves the emotional and textural aspects of participant response rather than objective, measurable behavior and attitudes (Moustakas, 1994). IPA uses a simple description and makes sense of participants' lived experiences by developing interplay analysis of the description in relation to social, cultural, and theoretical contexts (Callary et al., 2015). IPA also aligns with the purpose statement of this phenomenology inquiry by exploring and describing lived experiences and perceptions of eye bank coordinators when acquiring consent from family members of the deceased.

In keeping with IPA, the sample was small and homogenous. The participants had the same position within their eye banks. Two semi-structured interviews were conducted, which were audio-recorded, transcribed verbatim, and analyzed using IPA as described by Smith et al. (2009). Traditionally, qualitative research is a "means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2009, p. 4). Phenomenology research has a descriptive interpretation of an individual's experience. In this dissertation study, the goal was to discover the lived experience of an eye bank coordinator before, during, and after making a call to a beavered family to obtain consent for eye donation. Interpretative phenomenology analysis is "committed to how people make sense of their major life experiences; it is concerned with exploring experience in its own terms" (Smith et al., 2009, p. 1). Interpretative phenomenology analysis has been determined to be the most suited for this dissertation study as the investigator was attempting to explore the lived experiences of eye bank coordinators. The investigator was able to research the essence of an eye bank coordinator and understand how they are successful or unsuccessful in obtaining consent. Also, the investigator understood the attitudes and beliefs of the eye bank coordinators when making calls to families.

> IPA shares the view that human beings are sense-making creatures, and therefore the accounts which participants provide will reflect their attempts to make sense of their experiences. IPA also recognizes that access to experience is always dependent on what participants tell us about that experience, and that the researcher then needs to interpret that account from the participant in order to understand the experience (Smith et al., 2009, p. 3).

As previously stated, the focus of IPA is on "understanding personal lived experience and thus with exploring persons' relatedness to, or involvement in, a particular event or process" (Smith et al., 2009, p. 40). This dissertation study was used to answer the following questions:

RQ1. What are the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families?

RQ2. How do the positive and negative lived experience of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families?

## Research Assumptions

The research assumptions that were made for this qualitative dissertation study from the investigator's point of view was that the investigator has approached families for eye consent in the past. The investigator bracketed by journaling all prior experiences to ensure that there were no bias when analyzing the data. The assumptions from the participants' viewpoint were that they were willing to express all of their experiences (favorable and unfavorable) to the investigator, the participants were truthful and open with the investigator, the participants can be open and reflective with their experiences, and the participants felt confident that the information shared will be kept confidential.

## Reflexivity

Because of the personal experiences in researching about the topic, the investigator has developed personal opinions and familiarity about the process and experiences related to obtaining consent for eye donation from the family of the deceased. Because of these experiences, I have developed personal opinions that may incorrectly influence the findings of this study. Therefore, in this section, I discuss the different experiences, beliefs, and knowledge that I have gained in the past that may be related to the topic of this study. As the investigator, I have worked at the Florida Lions Eye Bank for 18 years. During that time I have had the opportunity to experience all aspects of eye banking, one of which was approaching families for eye donation. For the few calls that I have made, my experience approaching families was positive. I have not had a negative experience speaking with families; however, I have heard of many stories in which families called the coordinators names, were degrading, and rude on the phone calls. If I were to have had a negative experience, I would be reluctant to call another family for the purpose of obtaining consent for eye donation.

## Setting

When conducting interviews for IPA or any qualitative study, the investigator made sure that the participants were comfortable with the interview about to be conducted and that they felt safe in expressing their experiences. Also, the interviews were conducted in a neutral and natural setting, so the setting had high potential of gathering information richness. Traditionally, qualitative research is conducted at the site where the participants experience the issue or problem that is being studied. Qualitative researchers do not bring the participants to a lab or send out instruments for individuals to complete (Creswell, 2009). Smith et al. (2009) suggested that the participants be asked where they would like to conduct the interview. It is imperative that the participant is comfortably familiar with the interview site, and it must also be safe, reasonably quiet, and free from interruptions (Smith et al., 2009). Once the investigator felt that the participant was comfortable, the interview questions began. This study was conducted telephonically, and the investigator was at home while conducting the interview, and the participants were at a place of their choice. The participants being at a place of their choice while the interviews are being conducted ensured that the participants were uninterrupted and had enough time to complete the interviews.

## Sample Planning

Qualitative study sampling is purposively selected due to the nature of the research question and specific experiences the investigator was seeking. Two sampling technique were used for this dissertation study. The first was how the three eye banks were selected. These eye banks were selected by convenience sampling, meaning the investigator was familiar with these eye banks, the executive directors, and their process in obtaining consent. The executive directors of each eye bank received an invitation letter to the study (see Appendix B). The second part of selection for this study was snowballing; the executive directors allowed the investigator to contact their eye bank coordinators to invite them to participate (see Appendix C) in the study. Once the investigator had contact with the participants and verified that they met the inclusion criteria, the investigator invited the participant to participate in the study and fill out the necessary informed consent forms (see Appendix D).

## Participants

### Recruitment

The participants were recruited through purposive sampling based on a set of eligibility criteria. The investigator began by contacting the executive directors, inviting their eye bank to participate in the study, and obtaining email addresses for their eye bank coordinators. The investigator then sent a letter to the eye bank coordinators inviting them to participate in the study. All who were willing to participate were accepted to participate in the study. Only eligible participants were recruited for this study. Eligibility was based on a set of inclusion and exclusion criteria. These inclusionary and exclusionary criteria for the participants were included in the letter to the eye bank Executive Directors.

### Inclusion and Exclusion Criteria

The participants who were included in the study met the following criteria: (a) is an employee of The Florida Lions Eye Bank, San Diego Eye Bank, or Lions Eye Bank of Nebraska; (b) have been an eye bank coordinator who speaks to families for the purpose of obtaining consent for eye donation for at least 12 months to ensure familiarity with the process (Squires et al., 2014; Stitt, Brkljacic, & Rogerson, 2014), (c) have handled positive and negative responses from bereaved families of potential donors, (d) male or female, (e) any age, and (f) fluent in English.

Exclusion criteria for this study is any employee who works for the above mentioned eye banks who does not directly speak with families to obtain consent for eye donation. The criteria for inclusion and exclusion are aligned with characteristics of individuals that are needed to address the research questions about experiences of eye bank coordinators when requesting permission for eye donations from bereaved families.

### Sample Size

The suggested sample size for IPA is relatively small. The purpose of the small sample is because the goal of IPA is to describe a detailed account of individual experience; “the issue is quality, not quantity, and given the complexity of most human phenomena, interpretative philosophical analysis studies usually benefit from a concentrated focus on a small number of cases" (Smith et al., 2012, p. 51). Smith et al. (2012) suggested a sample size of three to six participants. For this dissertation study, the investigator utilized a sample size of four participants. This number was chosen due to the geographical locations of the eye banks chosen for the study. Each eye bank is in located in a different time zone across the United States. This diversity had a broad spectrum of experiences from each of the participants. This sample also provided a fairly homogenous sample, which was meaningful for the research question (Smith et al., 2012).

## Protections of Human Subjects

The primary investigator (PI) participated in the CITI training, disclosed all information to the Institutional Review Board (IRB), and followed all recommendations suggested by the review board. Also, no research began until the review board had reviewed and approved the study.

## Risks and Benefits of Participation

The participants could potentially be distressed by taking part in the study. The PI addressed any concerns the participants had prior to beginning the interview process. All participants had the right to answer or not answer any question they did not feel comfortable with. Finally, participants were able to take a break at any time during the interviews. Also, the PI reassured the participants that the study was completely voluntary, and they could withdraw from the study at any time. Finally, the information obtained from the study was kept completely confidential and not shared with the executive directors of participating eye banks.

## Data Storage

All data collected from the participants, including audio recordings and transcripts, were downloaded to an external hard drive, which was locked in a storage cabinet in the investigator's home. Once the dissertation study is completed, all data will be erased from the external hard drive. Also, the investigator was the only person who had access to the information. The step-by-step procedure for the data collection from recruitment phase to interview phase is presented in the succeeding sections. These procedures were identified in order to effectively recruit participants and collect data needed to address the research questions about positive and negative experiences of eye bank coordinators when interacting with bereaved families.

## Procedures

The researcher followed specific steps to complete this research. The steps were conducted as follows:

1. Upon IRB approval, the PI introduced the subject to the executive directors of three eye banks: Florida Lions Eye Bank, San Diego Eye Bank, and Lions Eye Bank of Nebraska. The executive directors provided the PI a list of employees who had contact with families along with their email addresses.
2. The PI contacted the eye bank coordinators to invite them to the study, herein referred to as participant, to sign informed consent form and informed the participant about confidentiality. Once the consent form was received by the PI, the PI then contacted the coordinator to set up a convenient time to conduct the interview.
3. Once the interviews were completed, the PI submitted the recordings to a professional transcriptionist to transcribe all interviews.
4. The transcripts were reviewed, and a second interview was scheduled to clarify or elaborate on any topics from the previous interview.

5. Once the second interviews were completed, the PI submitted the recordings to a professional transcriptionist to transcribe all interviews.
6. Coding began, and emergent themes were developed upon receipt of the transcripts.
7. Finally, a member check was conducted once the themes and their definitions were identified to ensure that they accurately represent the experiences of the participants.

The different data sources (e.g., demographics, interview question, field notes) used for this dissertation study are presented in the next section. The data collection was focused on collecting information about positive and negative experiences of eye bank coordinators when interactive with bereaved families.

## Data Collection

### Demographic Data

The demographic data that was collected during the interview process was background information regarding the number of years working with families, previous experience working with families, and their attitudes and perspectives are toward eye donation. The purpose for collecting demographic data was to provide background information about the participants of the study.

### Interview Questions

The interview questions were open ended. Each interview was audio recorded to facilitate easier transcription after each session. The investigator used an audio recorder, subject to the knowledge and consent of the participant during each interview.

The aim of the interview for IPA was to facilitate an interaction, which permits participants to tell their own stories in their own words; the participants talks and the interviewer listens (Smith et al., 2009). Also, questions should be expansive and open to prompt the participant to talk at length. With IPA, the number of interview questions should be between six and 10 and open-ended questions. The interviews should be between 45 and 90 minutes in length. A second interview was conducted for clarification and elaboration on any topics from the first interview. The interview questions that were asked during the first interview are listed in Appendix A. These questions are aligned with the research questions of the study.

To validate the items included in the interview, the investigator field tested the questions with two eye bank coordinators. During the field test, the investigator asked the two coordinators to pose as an interviewee using the initial guide questions. The investigator made sure that the mock interview for the field test was conducted in the same manner that the actual data collection interview was conducted. During the mock interview, the investigator took note of the items when a misunderstanding occurred. Moreover, the investigator also made notes of the questions for clarification that the participants would ask during the interview session. At the end of the interview, the researcher asked the participant if there were any particular item during the interview that was difficult to understand or caused confusion.

### Field Notes

The investigator journaled all thoughts during the two interviews. All notes reflected information that was learned or experienced through conversation with the participants (Richards & Morse, 2013). Notes were taken during the reading and rereading process of the data analysis as themes began to emerge.

## Data Management and Organization

All interviews were conducted telephonically due to the geographical locations of the participants. The interviews were recorded using a recording device that attaches to a phone and records both ends of the conversation. Even though the Florida Lions Eye Bank is located in

South Florida, the eye bank coordinators do not necessarily live in South Florida. The investigator hired a professional transcriptionist to transcribe all interviews. The interviews were transcribed verbatim, showing all words spoken by each of the participants. The purpose of transcribing the interviews was to ensure that the data used during the analysis were based on the actual words and sentences that the participants used during the interviews. For the purpose of confidentiality, the investigator asked the transcriptionist to sign a nondisclosure agreement, covering any data or information collected, analyzed, or used for this study. After organizing the information collected about the experiences of eye bank coordinators interacting with bereaved families, the data were analyzed using IPA.

## Data Analysis

The data analysis of this dissertation study was IPA based on the study of Smith et al. (2012). The first step in conducting the analysis was to read and reread the transcripts of the interviews as well as listening to the audio recordings. The second step was initial coding or open coding. Open coding is part of the early phase of data analysis wherein the analyst identifies relevant terms to reduce data into manageable segments (Olson, McAllister, Grinnell, Walters, & Appunn, 2016). For this study, during this second step, the investigator examined semantic content and language use on a very exploratory level; the goal was to produce a comprehensive and detailed set of notes and comments on the data that were relevant to answering each question (Smith et al., 2012). From these segments or basic phrases that address each research question, the investigator developed the coding systems to be used for the analysis of the entire data set (Smith et al., 2012). Overall, this first step documented the meaning to the participant. The comments were descriptive, linguistic, and conceptual.

The third step was developing emergent themes. The fourth step was the first half of axial coding, which is the process of connecting the codes and forming meaningful groups called themes (Fram, 2013). The main task in this step is to turn notes into themes and produce concise statement, which represents the psychological essence of the work. The investigator will identify possible groups of the codes (Fram, 2013). The themes are to reflect the participants' original words and thoughts as well as the investigators interpretation.

The fifth step is to search for connections across emergent themes. This step is the second part of axial coding wherein the investigator will identify potential associations between the formed groups of data. Once the emergent themes are identified across the cases (participants) and tables are created, the PI looked ok for connections and patterns across the cases. The relationships and patterns will be supported using existing literature. The PI looked for overlapping themes and themes that stand out the most. This step also involves selective coding, wherein the investigator reviewed all the themes and determine the ones that have a direct relationship to the research questions (Fram, 2013; Olson et al., 2016). Therefore, in this fifth step, the investigator developed a map of the how the investigator believed the themes fit together. Themes that were similar to one another became clusters. Abstraction was used during this process. Abstraction is a form of identifying patterns between emergent themes and developing a sense of a superordinate theme (Smith et al., 2009). The cluster became the superordinate themes. The investigator drew together the emergent themes and produced a structure that would include the most interesting and important aspects of the participants' account (Smith et al., 2012).

The sixth and final step was ascertaining patterns across cases. The investigator evaluated the cases to find connections between them.

To minimize bias during analysis, the investigator performed bracketing, which is the process of acknowledging personal experience, attitude, and beliefs, which are related to the topic of phenomenon being explored. The investigator kept a journal in which personal responses to the data collection and analysis were written. Through this process, the investigator has a basis of aspects to avoid for duration of the study, including the analysis phase, in order to prevent personal biases to interfere in the data collection and analysis for the study (Sorsa, Kiikkala, & Åstedt-Kurki, 2015).

## Trustworthiness and Integrity

Assessing validity and quality in qualitative research has brought much debate. Many researchers were not satisfied with how validity and reliability were applied to qualitative research. Smith et al. (2009) suggested Yardley's criteria in establishing quality for IPA research studies. For this dissertation study, the PI applied Yardley's four principles for assessing quality of this study. The four principals are sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance.

**Sensitivity to context**. This principle may show sensitivity to the socio-economic milieu in which the study is situated, the existing literature on the topic, and the material obtained from the participants (Smith et al., 2009). The PI showed sensitivity to context during the interview process by showing empathy, putting the participant at ease, and recognizing difficulties, which continued through to the analysis process by making sense of the participants experiences and by unfolding the participants' accounts and the information that can be learned from it (Smith et al., 2009).

**Commitment and rigor**. Commitment in an IPA study is demonstrated by the "degree of attentiveness to the participant during data collection and the care with which the analysis of each case is carried out" (Smith et al., 2009, p. 181). The PI was committed to the research and invested to the study to ensure that participant was comfortable and paid close attention to the information the participant provided about his/her experiences. Rigor refers to the thoroughness of the study in terms of the appropriateness of the sample to the question at hand, the quality of the interview, and the completeness of the analysis undertaken (Smith et al., 2009).

**Transparency and coherence**. Transparency refers to "how clearly the stages of the research process are described in the write-up of the study; carefully describing how participants were selected, how the interview schedules were constructed and the interviews were conducted, and what steps were used in analysis" (Smith et al., 2009, p. 182). Coherence is the degree of fit between the research that has been done and the underlying theoretical assumptions of the approach being implemented (Smith et al., 2009).

**Impact and importance**. According to Yardley, real validity lies in whether it tells the reader something interesting, important, or useful (Smith et al., 2009).

## Strengths and Limitations of Research Design

### Strengths

There are several strengths for using IPA to explore the lived experiences of eye bank coordinators before, during, and after speaking with families to obtain consent for eye donation. First, IPA was used for the investigator to gain an in-depth account of the participants' experiences. The open-ended questioning was used for the participants to freely talk about their experiences when speaking with families. Finally, the second interview was used for the participant to elaborate and/or clarify any comments that were made in the previous interview. The second interview also was used for the investigator to probe for more details in a comment that was made by the participant.

### Limitations

As there are strengths there are also some limitations to the study design. One limitation is the number of eye banks that were invited to join the study. The reason for limited number of eye banks was political. Many eye banks are reluctant to speak with other eye banks regarding the policies and procedures. Also recruitment of the participants was an issue. The investigator was unable to gauge how many people were willing to participate from these eye banks. Moreover, phenomenological research, including IPA, naturally involves the emotional and textual aspects of the particular response rather that objective, measurable behavior and attitudes (Moustakas, 1994). No standard procedure exists for interpreting the findings and research conclusions. Instead, interpretations and conclusions are based on the personal judgment and experience with phenomenological research. Nevertheless, the investigator made sure that the findings were valid through the process of bracketing, audit trail, and transcript review.

## Summary

The specific problem was that the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent were unknown. The purpose of this phenomenological dissertation study was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. To address the problem and achieve the purpose of this phenomenological study, the overarching research question was What are the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families? To address the research question, the investigator used a qualitative phenomenological research design. IPA studies are utilized to find the meaning of the lived experiences of a particular group of people. This group of people shares the same experiences and each of them will have a different account of those experiences. This study was designed to delve into the phenomenon of the experiences of eye bank coordinators before, during, and after making a call to families to obtain consent for eye donation. Thus far, there are no researchers who have evaluated the experiences of eye bank coordinators. In Chapter 4, the discussion is focused on the details of the findings from implementing the methods and procedures included in Chapter 3.

# Chapter 4: Results

## Introduction

Chapter 4 contains the discussion of the results of the interpretative phenomenological analysis of the interviews with the three eye bank coordinators. The purpose of this phenomenological study was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. Interviews with the participants were thoroughly analyzed to generate the themes addressing the main and two other research questions. To address the problem and achieve the purpose of this phenomenological study, the overarching research question was What are the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families?

### Research Questions

The main research question was then answered with the themes from the two other research questions below:

**RQ1.** What are the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families?

**RQ2.** How do the positive and negative lived experience of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families?

The chapter also contains a description of the sample, a brief discussion of the data analysis, the presentation of findings with the complete themes and verbatim responses of the participants and a summary.

## The Sample

Participants of the study were four eye bank coordinators who have at least a year of experience in their current position from three different eye banks (see Table 1). These participants when interviewed shared their dedication to their roles as eye bank coordinators. Further, participants overall had a positive perception towards their work as they believed they are able to do good and successfully help those in need upon completing their cases.

For Participant 1, his job pertained to "getting to help people. Well, it means a lot. I–I really–I really love what I do so it's kind of hard to put into words." Meanwhile, Participant 2 also believed in the positive impact of his job to others: "I think more than anything, I still like what we do has real impact in people's lives. And there is a lot of things that you could do that have impact." Similarly, Participant 3 connected her job with the ability to change other's lives: "It means that I change people's lives." Finally, Participant 2 used four words to express the meaning of his job to him: "It is dedication, motivation, perseverance, persistence."

Table 1
*Participants' Background and Experiences*

| Participant Number | Previous Experience in Talking to Grieving Families | Years as an Eye bank Coordinator |
|---|---|---|
| Participant 1 | None | 12+ years |
| Participant 2 | None | 34 years |
| Participant 3 | Was in social service, has experiences in speaking with victims, etc. | 1 year |
| Participant 4 | Volunteered in nursing stations | 11/2 years |

## Data Analysis

The four interview transcripts of the participants were examined using an interpretative phenomenological analysis with the aim of exploring, determining, and reporting the most significant experiences of the participants directly from their shared perceptions and during the interviews. The particular analysis has importance to the lived experiences of the participants, in this case, the firsthand knowledge of the eye bank coordinators when seeking consent from bereaved family members. As reported in the third chapter, Smith et al.'s (2012) six steps in completing an interpretative analysis were strictly followed. The first step was completed with the constant examination and reexamination of the interview transcripts. The second step performed was the noting or listing down of the relevant responses of the participants as well as their meanings. The third step included the development of the initial themes based on the notes and comments from the previous step. The fourth step used the data from the second and third steps to search for connections and relationships based on the meanings shared by the eye bank coordinators. In the fifth step, the themes and subthemes became more apparent, given the more detailed clustering of themes according to their meanings. The subthemes were the more thorough description of the initially formed themes. With the sixth and final step, the investigator again searched for more meanings and connections from the said themes with the final reporting of patterns found in the next section of the study.

## Presentation of Findings

### Research Question 1

Research question one was What are the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families? The first research question asked about the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families. The experiences of the participants were categorized into two aspects: the positive and negative experiences. The interpretative analysis led to the discovery of one theme and three subthemes under the positive experiences and three themes and four subthemes for the negative perceptions and experiences shared during the interviews. All participants shared the encouraging side of seeking permission for eye donations, which was their encounters with positive and enthusiastic family donors. These bereaved families are gracious and hopeful, despite their loss of a loved one. Meanwhile, three themes emerged in response to the negative experiences of the eye bank coordinators. For the majority of the participants, they believed the negative reaction should not be taken to heart as they must understand the situation or grief of family members. A number of participants added the difficulty when encountering closed-minded family members while one participant did not have many negative experiences. Table 2 contains the breakdown of the themes answering the first research question of the study.

Table 2
*Breakdown of Themes in Response to RQ1*

| Thematic Category | Theme | Sub-Theme/s |
|---|---|---|
| TCA. Positive Experiences | Encountering positive and enthusiastic family donors | *Turning their mourning or tragedy into a positive occurrence or outcome<br>*Having the awareness of the deceased's consent<br>*Being a witness of the family members' love for their deceased relative |
| TCB. Negative Experiences | Needing to understand the situation or grief of family members | *Being cussed out, yelled, insulted, and threatened by family members |
| | Encountering closed-minded family members | *Strong disbelief in the act of eye donation<br>*Feeling uncomfortable hearing the anger and antagonism towards the deceased |
| | Limited negative encounters experienced | *Lack of awareness on eye donation purpose |

*Note:* *Subthemes

**Thematic category A: Positive experiences.** The first category included the positive experiences of the eye bank coordinators. All coordinators shared their lived experience of having the opportunity to encounter positive and enthusiastic family donors. Three subthemes emerged, which presented how families were willing to turn their mourning or tragedy into a positive occurrence or outcome, the families having the awareness of the deceased's consent, and the coordinator being a witness of the family members' love for their deceased relative.

***Theme 1: Encountering positive and enthusiastic family donors**.* A key theme discovered was the lived experience of encountering positive and enthusiastic family donors. The interviewed eye bank coordinators shared how there are family members who are still gracious to listen to them, despite their difficult situation. There are family members who are willing to donate in order to turn their mourning into a better feeling, which is to give hope to others while there are those who want to honor their loved ones.

*Subtheme 1: Turning their mourning or tragedy into a positive occurrence or outcome.* One emerging subtheme was the experience of wanting to turn the negative occurrence or event into a positive outcome for the family members. The eye bank coordinators explained how there were families who were more than willing to share and make their loved ones' donors. As Participant 1 indicated, surprisingly, there are family members who can still react with compassion and kindness, despite the grief they are feeling. The participant shared how there are family members who want to help others and want their deceased loved ones to leave a legacy in this world.

> I've had families that have been very happy to make their loved one donors. You know, we approach on different cases whether they're registered or not registered. Registered cases, sometimes a family doesn't know and they're so happy that their loved one did register. It's like a big surprise. It's like, 'Wow, you know, that's wonderful. I'm so happy that he or she did that,' and, you know, they're really happy to follow through with their wishes and they're happy to make–make their loved one a donor. Other positive reactions are just that, you know, their loved one is able to live on through somebody

> else. They know that this is the right thing and that their loved one is, you know, able to help other people.
>
> I mean, so whether, you know, maybe–maybe their loved one had been in the medical field or maybe their loved one had been a researcher all of their life. What I do find is a lot of the cases that we approach on for research, when I call the families on those, the loved ones sometimes say, you know, 'My mother has wanted this forever. She gave her life to the community and she's always been very involved.' And so, this was something very special to their loved one to do this and to continue to give back even after they passed.

Further, Participant 3 shared another personal and most memorable experience of her career. The parents of a 24-month-old donor willingly agreed to donate, despite the great sadness and confusion they were feeling when Participant 3 called them. In the words of the father, he wanted to "see a positive thing" in the tragedy they were experiencing. For Participant 3, this experience was her most positive experience, given the very strong love and compassion demonstrated by the parent of the two-year-old donor:

> I think the first time I got a peds case that I was petrified. At the time I didn't have any kids, but I couldn't imagine what a conversation like that would be. This was on a 24 month old, so a two year old. I think it was the most nervous I've ever been in my life going into it, and I wanted to cry and run out of the building rather than do it. I ended up pushing through.
>
> It was one of I would have to say the most positive experiences I've ever had in having a conversation with a next of kin because when I called, the dad answered, and I approached him. Then the phone went silent, and in my head, I'm thinking, 'It's

> over. Get ready for it. It's coming.' He starts crying and he said, 'Can you repeat all that. I'm going to put you on speaker.' He said, 'Because my wife and I are sitting in the car outside of the hospital, and we're trying to figure out what could possibly be a positive thing in this.'
>
> 'Everything has just been so terrible for us.' He said, 'And what you just said to me…' he's like, 'This is a good thing that can come out of our tragedy.' So, I basically did my spiel again and the wife was listening. I could hear both of them sobbing and they were happy to move forward. That has been the one experience that for me stands out the most and it's probably the most positive.

*Subtheme 2: Having the awareness of the deceased's consent.* Another subtheme was the awareness of the deceased's or the donor's consent. Participant 2 shared how it is always a positive experience when dealing with family members who are well aware of the donor's consent to donate his or her cornea. The participant narrated how the awareness of the family members leads to a smooth process of donation or case and only the standard explanations and protocols are needed:

> And so, you have the one side where maybe you have a first-person consent and the family knows that that person wanted to do that and are completely onboard with that. There is really no discussion at all, it's a matter of okay, what about you and so you go through the process. You've got families who have a lot going ahead of the first person and they had no idea.
>
> And they just so you explain what would be involved and they still go forward. And what I mean by going forward is allowing us to do a donor risk assessment interview, which to a degree they control, and they still have some control in the process. And families that

> haven't felt about it at all the exact basic information they speak with their family and with it both. Most of the time though I will say at least in those situations majority vast, vast majority of families are incredibly gracious at the time that we talk to them. And the number of times that we get someone who is rude, or impatience is and I don't approach families as much as I used to because I don't primarily work in a coordinator role anymore.

*Subtheme 3: Being a witness of the family members' love for their deceased relative.* The final subtheme was the experience of being a witness of the family members' genuine love for their deceased loved ones. Participant 4 also shared her most remarkable and emotional case as a coordinator. The participant was a witness of a husband's undying love for his wife. Even though he was still overwhelmed with grief, he was still able to show empathy by agreeing to donate not only his wife's corneas but her tissues as well. Participant 4 also found the case to be motivational as he realized the kindness and gentleness of individuals despite their loss:

> So, there is a specific case actually the couple–the first couple of months, I think within the first three months of me working as a coordinator and at the time I was just signed off. I was doing everything on my own. And I remember specifically this moment, this next of kin was a husband and his wife had just passed away, and the way that he spoke about–he donated absolutely everything from–she was 40 something so she qualified for basically everything in the tissue bank and obviously for corneas.
>
> But the way that he spoke about donation and about the way how he spoke about his wife just showed so much love, and I thought that you know, what he was giving was way too much for what the amount of love that he expressed about her, and he was crying. And that was the most probably the most emotional part I–one of the most emotional cases I've ever had to endure because of how overwhelming it was for him.

> And that was a positive experience because even after talking about his wife as a princess, as his one and only love, he still managed to get through the questionnaire, the medical social and the authorization form, which I had to read the entire thing that is probably the most motivational one. Like if he can do it, then, of course, a lot of other people can do it even with not as close of a relative or loved one.

**Thematic category B: Negative experiences.** The second category was the negative experiences of the eye bank coordinators. From the analysis, participants had various experiences generating three themes and four subthemes. Three of the four participants expressed how family members will normally have negative reactions, and as coordinators, they must have the ability to understand the situation of the family members and compose themselves to perform their responsibilities. Further, two participants also shared how it is challenging to approach and convince closed-minded family members. Lastly, one participant shared how he had limited negative experiences with the family members of the donors. Each of the subtheme will be discussed further below.

***Theme 1: Needing to understand the situation or grief of family members.*** The first theme under the second thematic category was the need to understand the situation or grief of the family members. As experienced eye bank coordinators, the participants demonstrated the proper reactions and answers to the family members, despite the negative response to their proposition. Participants 1, 3, and 4 explained how they have been trained to manage these situations, and as human beings, it is but natural for the family members to have negative reactions and responses when approached about donations immediately after the death of their loved ones. Simply, Participant 1 related anger with the grief process of the family members.

The participant added how each person deals with the loss of a loved one differently, and having negative reactions, sadness, or anger is normal:

> Other times, you know, families are angry just because they are going through their grief process and I–I mean, I honestly believe it's just where they are in the grief process. Everybody grieves differently and even though there is the different steps of grief, everybody kind of hits those at different points. And even though we're calling families all pretty much at the same time within that 24-hour period, everybody is kind of doing something different. You know, they're really angry or really sad, just kind of–just depends on where that family member is at that point.

*Subtheme 1: Being cussed out, yelled, insulted, and threatened by family members.* One subtheme under the key theme was the experience of being cussed out, insulted, or threatened by the family members. Participants 3 and 4 shared how they have encountered family members who are unable to control their emotions. Participant 3 has heard of insults and other negative comments from the family members; however, he added that this lack of control was already expected:

> No, yeah, yelling no, I've had a couple of people yell, and they're upset, but nothing that was so negative that–no I can't say that I've had that. I've had people yell and hang up, and insult you, and cuss you out, but for me, that wasn't going to–I mean it's expected, especially with the timelines we hold, but yeah.

Meanwhile, Participant 4 shared another unique experience in which the family member even involved the participant and blamed everyone at the hospital for her uncle's demise. The participant narrated an experience in which the said family member could not control herself and had to be reported because of her threats. However, the participant still constantly highlighted how as a coordinator, he understood that people grieve and manage their emotions differently:

> Negative would be the next of kin that is grieving terribly. I have an experience where the next of kin is, well, said that she was close to her uncle. It was kind of an odd situation, but she did swear at me, cuss at me for five minutes straight just saying that the hospital had killed her uncle. But the man was about 80 something years old. He was closer to 90, which I mean I understand everyone grieves differently. It was just–I just didn't understand it from her perspective at the time especially since I was very polite to her.
>
> And then I did have an even serious situation where a next of kin threatened to shoot up a hospital because she was so upset. I think it was her sibling, sister, but I'm not sure, that had passed away and she again blamed–also blamed the hospital for killing them and that she said that she is going to shoot up the hospital and the physician that was attending them. And of course, it was something that I had to report and that is just really the most negative side of it, the blaming part of it of how they're grieving and who they have to blame not wanting to talk to anyone.
>
> I alerted my supervisor and then the executive security. A manager at the hospital contacted me just to get a statement, which I did give them a statement. And then they said that they were going to take care of it. But I immediately had to tell someone about it so that they could at least be alert just anything were to happen which I think nothing happened. But that was as far as I ever heard about that again.

***Theme 2: Encountering closed-minded family members.*** The second theme that emerged was dealing with closed-minded or traditional family members. Two participants shared how there are still many who are unaware of the purpose and process of the eye donation while there are some who cannot control their feelings of anger with the passing of their family members. In turn, eye bank coordinators have a difficult time relating to the members and relaying their messages accordingly.

*Subtheme 1: Strong disbelief in the act of eye donation.* One subtheme presented was the difficulty in dealing with members who strongly disagree with the act and purpose of eye donation. Participant 1 shared his lived experience of dealing with family members who did not want their family members to undergo the donation as they wish to "respect the body" of their loved ones. The participant found this interesting and stated

> So, man, there have been, you know, the scenarios can be–there can be a million different scenarios that can range anywhere from, you know, I want–the one that sticks out with me that is always interesting to me is when the family member say, "You know, I want them to go back into the earth as they came." I just, I don't know, I mean, I find that interesting. I–it is hard to, I mean, it's hard to try to get them to see the positive in eye donation because they're just struck on, you know, they just have to go back naturally.

*Subtheme 2: Feeling uncomfortable hearing the anger and antagonism towards the deceased.* The second subtheme that emerged was the experience of being the receiver of the anger of family members toward the deceased. Participant 3 narrated the uncomfortable experience of listening to a son cursing at his deceased mother. The lack of respect and love for the mother was astonishing, and the participant considered this a negative experience rather than being declined by the family members:

> I think that–you know, it was just a very uncomfortable–not the most negative, but I would say it was a negative in the sense that it impacted donation. We actually got

> consent, but I had to do the interview with the son of a–I think she was like a 60-year-old female, and it was his mother. He referred to her as 'That bitch' the entire time.
>
> It was like his hatred could come directly. We ended up–I mean that donation ended up going in research, but it was just one of the most uncomfortable because it really–personally, it was really driving me nuts, you know? Yeah, at a certain point. What it came down to is I think he had had issues in the past, and she just never supported his lifestyle. He decided that he was going to leave school and she was against it, so she cut him off financially. He said, 'I suffered for many years.' He's like, 'And now I end up keeping it all.' I mean it was bad. I'm like, 'Jokes going to be on you if she had left everything to her dogs.'
>
> No, but yeah, yeah. And he said, 'If you want to take anything else if you want to kick her bones, cut her up…' He's like, 'I don't care because I'm going to burn her anyways.' I mean it was uncomfortable. That was one of those times where it taps into your personal space, but yeah, I think that was the worst.

***Theme 3: Limited negative encounters experienced.*** The last theme for the first research question was demonstrated with the experience of Participant 2 who had encountered limited negative experiences. In particular, the participant stated that negative experiences usually just stem from the lack of awareness of the people, which can usually be managed or solved through a careful discussion with the family members. Additionally, Participant 2 believed how negative situations can be addressed by properly communicating and educating the family members about their purpose:

> But I think part of that is the fact that I think our culture has changed and the fact that it isn't something that is still foreign to people anymore. I've certainly had on rare

> occasion, a family who was put out and angered by the fact that we were calling or misunderstood what the term donation meant. And they initially understood oh, a donation oh, yeah, we'll take anything you can give us to which you then have to explain to them, 'Well, no, we're not calling to donate to you, we're asking in the other direction.'
>
> And in those cases, I've had some very coarse and negative responses. But as a percentage of the families that I approach I would say that's probably less than 2 to 1% that they would have any kind of a negative response. Other than that, either they're saying no, we're not interested. But I don't consider that a negative response, you're giving me an answer but they're not doing or getting on.

## Research Question 2

The second research question was How do the positive and negative lived experience of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families?

The second research question was used to explore how the positive and negative lived experiences of eye bank coordinators influenced their adjustment of strategies when requesting permission for eye donations from bereaved families. From the analysis of the interviews, two categories were again formed: the positive and negative experiences and how these experiences affected their strategies. Three themes were generated in discussing the positive experiences and another three themes with five subthemes under the negative experiences. Participants shared how the positive experiences would give them the energy and motivation to seek more donors as well as the reminder to ensure that the right information was conveyed to the families. One participant relayed how the positive experiences allowed him to become more comfortable and at ease when requesting permission. Consequently, for the negative experiences, all participants believed the key strategy was to constantly work to ensure they were communicating and conveying the correct information to the family members. Other emerging themes were coaching and collecting oneself back and knowing how to read the actions and reactions of families. Table 3 contains the breakdown of the themes in response to the second research question.

Table 3
*Breakdown of Themes in Response to RQ2*

| Thematic Category | Theme | Subthemes |
|---|---|---|
| TCA. Positive experiences | Having the energy and motivation to seek for more donors | |
| | Ensuring the right information is conveyed to the families | |
| | Feeling more relaxed and comfortable | |
| TCB. Negative experiences | Continuing to explain and ensure the correct information is conveyed | *Using more sensitive and simple terms<br>*Answering the questions of family members |
| | Coaching and collecting oneself back | |
| | Knowing how to read the actions and reactions of families | *Being courteous and moving on to other families<br>*Modifying strategies based on initial reactions |
| | Learning from experiences and becoming more cautious | |

*Note: *Subthemes*

**Thematic category A: Positive experiences.** The first thematic category contains the discussion of how the positive lived experiences of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families. The participants' experiences varied with the emphasis on working even harder to encourage more donors and achieve their goals accordingly. During the interviews, the participants expressed how the positive experiences became their motivation to help and save more individuals in need of a transplant.

***Theme 1: Having the energy and motivation to seek for more donors.*** The first theme under the second research question was the strategy of working harder to seek for more donors, stemming from the good energy from their positive encounters and experiences. Two participants (PA1 and PA2) shared the said experience. Participant 1 described the feeling of becoming even better when more and more people agree for their family members to become donors. He believed the "yeses" are sources of encouragement to do even better. Further, he explained how he does not get affected by the negative experiences but the "no's" can partly influence his emotions towards work:

> So, when I'm getting a lot of people saying yes, it kind of becomes like a high. You're just really like rolling with it and you–I just–it's very encouraging to continue to get more and more and more. You know, the days when I have multiple good conversations with families are really great. It's a great feeling and once I start approaching and I get good results, it–I feel like I do want to keep calling families, I mean, and I think those are my best days.
>
> On the negatives ones, it becomes a bit of downer, it really kind of does. It encourages me to try to get consents, because you know, really, you don't want to have–you don't want to have several declines in a row, because it's really a downer. But I don't think it affects my ability, or I don't think it affects the way that I do my job; I don't know. I think it–it definitely affects my, like, emotions, because I become a little upset when they continue to decline.

Meanwhile, Participant 4 also echoed the positive feeling upon interacting with loving and accepting family members. Being open to donations made Participant 4 believe that more and more people are becoming charitable and interested in helping others, making their job more meaningful and respectable. The participant narrated

> Yes, exactly because–right. So, I'm motivated more by the positive side of everything because I feel so heartwarming when I'm speaking to a family that is so open to donating anything and everything possible. It just tells a lot about them. And it definitely does outweigh the negative because a lot more people do authorize. And those cases like the one where the old lady wanted to shoot up a hospital, that I just know that not everyone is going to be like that and that is just one family member grieving that way. So definitely I have to keep a positive mentality.
>
> I definitely feel impacted, a positive experience like being thanked. I've been told that what we do is hard and that they very much appreciate taking the time to call them and it really makes me validate what I do that others can see the good in it besides us to see how we can help others. Of course, I know more what is going on, but even then, people think that if they thank me for what I'm doing, it really stays with me forever. Like I do think of that one case that I told you was my most positive experience was the next of kin that lost his wife, that really stays to me till this day, so pretty much forever.

***Theme 2: Ensuring the right information is conveyed to the families.*** The second theme that emerged was the strategy of continuing with the usual protocol and ensuring the right information is conveyed to the family members, despite the initial positive response. For Participants 3 and 4, they were not discouraged by the negative reactions of the family members; however, no matter which situation they are in, they always warranted that the other party was well aware of the details and information about eye donation. Participant 3 believed that once the family members were knowledgeable of the purpose of eye donation, and they are given all the details needed, and the decision is left for them to make:

> Neither one of them has discouraged me. If anything, I think in both situations and even then, people find whatever terms they need to come to with donation. I just want to know, and I want to make sure that I'm giving them the information so that they make whatever decision that's best for them. I don't think either experience–I think if anything my good experience has pushed me to see peds cases in a completely different light, so neither one of those two have negatively affected my feeling towards approaching families.

Another participant (PA4) felt more comfortable and at ease once all information and details were relayed to the family members. If the members were willing to listen, Participant 4 will then push forward and explain the process accordingly:

> I definitely feel more comfortable. We do–I am able to give as much detail as possible to them to explain really that what happens, the process. So, since they're more open to it and they want to hear me, then I will definitely go for. Besides pointing out the main points of donation, I'll go ahead and explain to them more like the timing of the surgery–of the recovery, what will happen, what we need to do, and who I can to the people I work with. So, I just take my time talking to them the details.

***Theme 3: Feeling more relaxed and comfortable.*** Another theme that emerged was the feeling of being more relaxed and comfortable, resulting in better work productivity and results. Only one participant shared this experience. For Participant 1, it was important to adjust depending on the reaction of the other party. With a positive feedback, the participant became more comfortable to send his message across to the family members:

> You have to definitely have to adjust constantly, I think, throughout the whole conversation. So, after my initial approach, if it's very positive feedback, I can tell you that I'm usually way more laid back because, at that point, it's like, okay, so we're on the same page, you know, we're just going to get through this now.

**Thematic category B: Negative experiences.** The second thematic category presented the negative experiences of the participants and how they modified their strategies in communicating with the bereaved family members. With the analysis, three themes and five other subthemes were discovered. All participants reported the experience of needing to have the determination and patience to continue to explain and ensure the correct information is conveyed. Participants also believed in the effectiveness of coaching and collecting oneself back when the usual strategies were not working as expected. Additionally, participants reported the significance of knowing how to read the actions and reactions of families and adjust their styles accordingly.

***Theme 1: Continuing to explain and ensure the correct information is conveyed.*** The first key theme under the second thematic category was the strategy of continuously working to ensure that all details were communicated to the family members. For all of the four participants, they believed in the effectiveness of restructuring of words, questions, and approaches when the family members were unclear of the coordinators' purpose. Participant 1 shared how the lack of clarity and miscommunication made him more motivated to explain the meaning of eye donation better. For Participant 1 the declines made him wonder about certain methods about how he could improve as well as the information or words that he could use to convince the family members:

> So, yes, no. I do try to get them to understand. Sometimes it works, sometimes it doesn't. It does make me continue to try to explain to them, but sometimes they're just really angry and they, you know, they don't want to hear it and they disconnect the call. And when I get a decline, I really do feel like the family is just like not listening. I mean, I get that some people just don't believe in donation, but I feel like maybe if I could have explained it a little bit better, maybe if I could have just gotten through to them, if they would have just let me explain it a little bit more and I'm always wondering, you know, what can I say differently, how can I get those right words in at the right time for them to understand what I'm saying.
>
> And when it's a negative reaction, right off the bat, I'm definitely more–just more–you're not warmed up, but just more on top of my game. Like, you know, now I have to–now I have to prove something here. I have to–I have to make them see what's happening. You know, I have to really give a good explanation of what we would like to do and the benefits, you know, it's like I have to get my game face on to make this happen.

Further, Participant 3 echoed the same strategy and shared how multiple declines can pertain to the need to collect and share more information about eye donation to the family members. Aside from the collection and sharing of information, Participant 3 also found it crucial to cater the needs of the family members and address them accordingly:

> It's funny because for me when I have a negative experience I just walk away for a minute, it doesn't affect my personal confidence. What does get to me is when I have multiple declines in a short period. Like if I start my day and the first two, three off the

> bat are declines, that makes me wonder, "What state of mind are you in right now that for some reason maybe you're not bringing the information across correctly?"
>
> Those are the things that do affect me, but when I've had negative conversations with families, personally, it doesn't shake my confidence. It's when there's multiple encounters and it feels like maybe I'm not bringing my point across or I'm not bringing the information in catering it to the family the way I should have in order for them to make the decision that we would have expected.

*Subtheme 1: Using more sensitive and simple terms.* A subtheme that emerged was the need to use sensitive and simpler terms when speaking with the family members. Participant 2 narrated how he usually started his conversations with the family members by carefully explaining the purpose and process of the donation. He shared how he tried to be as clear and simple as possible in order to ensure that the family members could comprehend the procedure, despite the medical terms and background of the subject. The participant also provided an example in which

> And so generally what I'm going to do is to say that it's my primarily responsibilities to make sure that they have all information that they need, and so can I go ahead, and I guess to provide a little bit more information and I just want to make sure that you're aware what the process is. I don't get into a lot of detail. You have to be sensitive it's a surgical procedure and I get into that aspect to try and really select your language in a way that it's hopefully both informative but also nongraphic and is sensitive to the family. And in all honesty, I try and speak, and I make sure that I don't speak in medical terms and I'm trying to speak on a fairly elementary level I guess using analogies if I have to. If they say what I ask it's still exactly what it is I cover.

> Well, I try and use things that are very relatable at least the tissue perhaps the size of a dime or something the size of and larger than a contact lens, those kinds of things. So, we'll probably give a little bit of information and/or if I get to a sense that they're fully aware of this and they're happy to do it and what's next. I may just go very say a couple of things very briefly as far as details. But then say, okay, well, basically what we need to do is we need to do a consent which I can do over the phone with you and then I need to do a medical social interview which will take so many minutes. And we have some time here you tell me what the best way is to be able to do this if you have time now that's going to take this much time if you have other things to do when will be an appropriate time to call back. So, if the family is supportive and positive I probably less have to get into detail. If a family is a little bit more negative, then I may simply ask their permission to at least provide them with a little basic information about what their options may be.

*Subtheme 2: Answering the questions of family members.* Another theme that followed was the strategy of ensuring that all questions or queries of the participants were addressed by the coordinator. Participant 4 believed in the importance of sharing all the pertinent information and in the process, answering the questions and doubts of the family members must be done as well. The participant stated:

> Every day I try to set to be as positive as possible if consent comes of it. It makes me want to try my hardest of the entire day. And if I get a decline and those have the negative families, it definitely does discourage me for a while of my–during the time I'm working. But of course, I just try harder knowing that everyone is different. I'm just

> giving them the information to the best of my ability, answering their questions and then the decision after all is theirs.

***Theme 2: Coaching and collecting oneself back.*** The second theme that emerged was the strategy of coaching and collecting oneself back, which is to reorganize and identify if the coordinator missed a crucial information or step in the process. Participants 1 and 4 shared how it is helpful to stop for a while and collect oneself in order to determine the issues or the issues that went wrong in the process. Participant 1 admitted that it could be discouraging at times, but he has learned to coach himself back to fulfill his responsibilities and overall goals as a coordinator:

> I kind of–it goes both way, that sometimes when I've had a lot of declines and a lot of negative reactions, I do get in a little bit of a rut. It's like, you know, I'm not doing as well as I want to be and it's–I've thought about this a lot is that, like, I just to have like coach myself back. Because it seems like when I start getting declines, I don't get just one. It's like I'll get like several in one day. And so, I do wonder why that happens. Is it something that I'm doing because I've had ones and now maybe, I mean, I don't know. But it does become a little discouraging when there is, maybe, you know, a couple, not just one. Maybe a couple, yeah. It becomes a little discouraging.

Further, Participant 4 believed that readjusting would work if the family members may have missed a crucial detail or information. However, it should already be ineffective once members show or demonstrate a firm "no" to his proposal:

> I try to be as helpful as possible for those that are a firm no. I have to like to readjust myself and just really get to the root of it, understand why they're saying no, why is it a firm no. I won't try to push it, like I would just accept the firm no's, because either–

> oftentimes it has been no, they–I knew that they did not want to donate. And I don't think it is easy for someone to say, "I don't want to donate," because it says a lot about their character. So, I think–so those firm no's, I would just take. I won't really readjust.

***Theme 3: Knowing how to read the actions and reactions of families.*** Another theme that emerged from the analysis was reading the actions and reactions of the family members and readjusting accordingly. For the three participants, they believed in the importance of respect and courtesy as well as being capable of quickly reacting and restructuring of practices based on the responses or actions of the family members. Each subtheme is discussed below.

*Subtheme 1: Being courteous and moving on to other families.* The first subtheme generated from the analysis was the need to be aware of when to stop and move on to other donors in order to show courtesy and respect to the bereaved families. Participant 2 shared how he was always prepared to hear and see the reactions of the family members. For Participant 2, once all details about the process were completely and clearly shared and the family members were given the opportunity to decide for their loved ones, coordinators must be considerate of the situation of the family members and move on:

> Again, I've been at this long enough to where I clearly understand that I don't have any idea what the person on the other end of that phone is going through right now. And so, I'm kind of prepared for anything and any type of response that they would give me if it's emotional or whatever I would completely understand. So, I don't believe I get flustered by a response like that other than did you simply say. And I think that's one of the values of the way that we do is simply say, please understand, the reason that I'm calling is simply to provide you with information and an opportunity to make a decision about the donation process.

> And if you still not interested and still angry then that’s fine that doesn’t change my opinion or my approach or add an additional twist and I get the next in the call balancing. Do you know? I have a job and I have a job to be courteous and kind to this family and to let them know what an opportunity that you have, and we can forward that for them if they would like us to do. And if they don’t, then I’ve done my job as well. So, it doesn’t determine, it doesn’t change my attitude I don’t believe even if I get a very strong negative response.

Meanwhile, Participant 4 added that it is also vital to assist and be helpful to the family members, especially to those who strongly decline the donation process. The participant tries to speak with the family members and determine the main reasons as to why they are declining. However, once the family members have decided with a firm no, the participant does not readjust and moves on to the next possible donors:

> I try to be as helpful as possible for those that are a firm no. I have to like to readjust myself and just really get to the root of it, understand why they’re saying no, why is it a firm no. I won’t try to push it like I would just accept the firm no’s, because either–oftentimes it has been no, they–I knew that they did not want to donate. And I don’t think it is easy for someone to say, “I don’t want to donate” because it says a lot about their character. So, I think–so those firm no’s, I would just take. I won’t really readjust. I never do ask questions, only readjusting like why you are saying like just asking what their concerns are. That is really how I readjust a lot of the times to try to make it as more and more possible by saying, well, families have expressed that before. And then I don’t readjust when there is a firm no, like I–they repeat it because no they did not want to donate, I know that for sure. Or they have–they said they had an advance directive

> where they specifically said no to donation and they will say oftentimes, 'I'm sorry, I am for donation, but she or he was not.' So, then I don't even try to ask them why and just back off and accept that that is their decision.

***Theme 4: Learning from experiences and becoming more cautious.*** The final theme that emerged was the strategy of learning from their past mistakes and experiences as a coordinator and applying them to become more cautious going forward. Only one participant shared the theme. Participant 4 shared he does not become disheartened with the declines. However, the declines serve as lessons to do better as he moves on to the next donors:

> But I definitely do get discouraged and it made my approach different and I learned from the way I'm approaching all of this way, I shouldn't approach a similar situation like that again or I should be more cautious about this and this. But that is how I pretty much think of it.

## Summary

The fourth chapter contained the results from the analysis of the interview with four eye bank coordinators. The purpose of this phenomenological study was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. The careful analysis of the interviews led to the discovery of themes addressing the central and two other research questions of the study. Overall, four themes and seven subthemes were discovered in response to the first research question and six themes and five subthemes were generated addressing the second research question. All themes were generated to answer the central research question, which explored the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families. In the final chapter, these themes will be discussed and explained in relation to the literature in the second chapter.  Further, the implications, recommendations, and conclusions are also found in the fifth chapter.

# Chapter 5: Discussion

## Introduction

This phenomenological study was conducted to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching family members for consent for eye donation. This investigator wanted to find meaning in the lived experiences of the participants by conducting phone interviews about the phenomenon of requesting for permission for eye donation from the bereaved family members during the grieving process. It bears noting that there are only few researchers who examined the experiences of the eye bank coordinators before, during, and after making the phone call to request for donation from the families. The main research question was then answered with the themes from the two other research questions.

### Research Questions

**RQ1.** What are the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families?

**RQ2.** How do the positive and negative lived experience of eye bank coordinators influence their adjustment of strategies when requesting permission for eye donations from bereaved families?

Based on the findings of the study, the participants shared the encouraging side of obtaining the required permission for eye donations. However, there were also themes suggesting that there were negative experiences relating to the coordination with eye banks. The participants also shared how the positive experiences give them the energy and motivation to seek for more donors as well as the reminder to ensure that the right information is conveyed to the families. The information and findings gained from this research may help eye banks develop a training program to help coordinators speak to families.  The task of an eye donation coordinator may be interpreted as to include other factors, such as knowing how to sympathize with the family members, while enlightening these individuals of the benefits and significance of eye donation. The results of the study will be used to promote positive social change because the results will benefit different stakeholders, such as the eye banks, hospitals, the ability of the grieving families to cope, and more importantly, the possible beneficiaries of the donated organ.

## Interpretation of the Findings

The first research question inquired about the positive and negative experiences of eye bank coordinators when requesting permission for eye donations from bereaved families. It can be noted that the positive and negative experiences of the eye bank coordinators who were interviewed in this study may have been influenced by the way they approached the family members. The experiences of the participants were then categorized into two aspects: the positive and negative experiences. Thus, it can be noted that the reactions of the family members may not have been independent of their perceptions, but actually influenced by the skills and dispositions of the eye bank coordinators.

The participants found that being able to encounter positive and enthusiastic donor families helped in negotiating for the family to positively respond to the donation of an eye. Hogan et al. (2014) were able to demonstrate that bereaved family members follow the normal pattern of grief, which the eye bank coordinators who participated in this study had to understand in order to successfully communicate with the family members. It can be noted that the ability of the eye bank coordinators who participated in this study would have been able to recognize the pattern of grief of the family members. The interviewed eye bank coordinators shared how there were family members who were still gracious to listen to them, despite their difficult situation.

There were family members who were willing to donate in order to turn their mourning into a better feeling, which is to give hope to others while there are those who want to honor their loved ones. Thus, for the participants in this study, it was important for them to recognize the proper approach, which was made possible by their skills and training from their educational background or from their experience in their profession and line of work.

The awareness on the part of the eye bank coordinators helped the family to understand the necessity of eye banks without feeling pressured to favorably agree to the donation of eyes. Verbal and nonverbal communication is an essential form of communication for health care providers. Siminoff and Step (2011) described a computerized program to facilitate the analysis of health care conversations. Based on the experience of the participants, health care conversations made the family members become more trustful of the process of eye donation. Thus, it was recognized by the participants that it was actually important to open the line of conversations about health.

The coordinator's perception of the family's reaction is important in the success of the possibility of donation. Rodriguez-Villar et al. (2012) studied the coordinator's perception of next-of-kin's reactions during family approach for tissue requests and its correlation to donating tissue and refusal to donate. Thus, the participants of the dissertation study noted the importance of managing how the families would react to eye donation. My findings are consistent with available literature because past researchers have all emphasized the importance of communication skills in coordinating with the family members. Nonverbal and verbal communication can convey multiple layers of messages (Siminoff & Step, 2011). Based on the lived experiences of the participants, the eye bank coordinators noted the importance of the way they approached the family members also focused on both the verbal and nonverbal aspects of communication. The dissertation findings were able to confirm that nonverbal communication skills are equally important to ensure that the eye bank coordinators performed their job properly.

The findings are consistent with Traino and Siminoff's (2012) findings because they found that the knowledge of loved ones' wishes regarding donation aided the families in their decision making, increased the likelihood of familial authorization and satisfaction with the final donation decision, and did not add additional stress to the already bereaved families. The participants of the dissertation study confirmed that awareness of the challenges encountered by the families helped in the coordination for eye donation. Whisenant and Woodring (2012) found that some nursing programs offered courses in transplantation as electives, which helped some eye coordinators who had this background to perform better in coordinating with families. The findings of the dissertation study may be linked to available literature because training was likewise emphasized by the participants as an important factor.

Zheng et al. (2012) stated that a significant number of American medical schools were unable to provide instruction for implementing different processes on donation, such as consent processes, definitions of brain and cardiac death, and the discussion of organ donation during routine health care visits. Zheng et al.'s (2012) findings may be linked to the negative experiences experienced by the eye bank coordinators who were not given proper instruction by the medical schools. The eye bank coordinators also experienced negative encounters, such as being insulted or yelled at by the family members. Some also lacked the awareness that the request for eye donation had an altruistic purpose. Three of the four participants expressed how family members will normally have negative reactions, and as coordinators, they must have the ability to understand the situation of the family members compose themselves to perform their responsibilities. Further, two participants also shared how it is challenging to approach and talk to closed-minded family members. Lastly, one participant shared how he had limited negative experiences with the family members of the donors.

Peltier et al. (2012) showed five factors that influenced support for organ donation, and/or organ donor registration, which includes (a) awareness of organ donation, (b) whether college students acknowledge a need for organ donation, (c) college students' perceptions of the benefits organ donation, (d) college students and their social networks' willingness to provide social support for organ donation, and (e) concerns about donation held by college students. The factors may have also influenced the decision of the family members who interacted with the participants of the study. Thus, the different motivations may have influenced the positive or negative decision to continue with eye donation.

The second research question presented the positive and negative lived experiences of eye bank coordinators and how their experiences influenced their adjustment of strategies when requesting permission for eye donations from bereaved families. From the analysis of the interviews, two categories were formed: the positive and negative experiences and how these experiences affected their strategies. Three themes were generated in discussing the positive experiences, and another three themes with five subthemes under the negative experiences. Participants shared how the positive experiences gave them the energy and motivation to seek for more donors as well as the reminder to ensure that the right information is conveyed to the families. Some families found solace and comfort through donating their loved ones' organs, and for others, donating does not have any impact on their grieving process (Beard et al., 2002). The perceived lack of impact to the grieving process may be attributed as one of the reasons for the agreement and consent obtained from the family members. One participant relayed how the positive experiences allow him to become more comfortable and at ease when requesting permission.

Lawlor and Kerridge (2014) found that people often associate eyes with visibility, identity, and beauty. Participants in the study stated that when considering organ donation and eye donation, they distinguished that organs are not visible, and therefore, there was no discomfort with organs being removed. This perspective based on the study conducted by Lawlor and Kerridge (2014) cannot be confirmed based on the findings of this study. The focus of study was not on the primary reasoning for the agreement or lack of agreement from the family members. The participants noted that it was important to have the energy and sufficient motivation to be able to seek for more donors, which would benefit the eye banks.

The participants likewise noted the importance of being able to convey the right information to the families. The ability to convey the information allowed the families to feel more relaxed and comfortable in their work. The consent to donate eyes to eye bank coordinators may be characterized as efforts made by the families to restore peace, are helping others live, improving the recipient's quality of life, fulfilling the wishes of the deceased, and creating a living memory of their loved one (Manuel et al., 2010). The dissertation findings are consistent with Manuel et al.'s (2010) findings because the consent secured from family members may have been driven by the desire of the family members to continue the living memory of their loved ones.

Giving the family time after the notification of death may result in increased eye donors. Niles and Mattice (1996) suggested that families must be given enough time to accept the death of a family member before they are presented with the option of donation. This situation has been confirmed by the dissertation study because based on the experience of the eye bank coordinators, the reaction of the family members to them seeking consent for eye donation was mainly influenced by the timing. The timing of the approach for donation might be critical in obtaining consent from families (Niles & Mattice, 1996). The lived experiences of the participants noted that timing was important in ensuring that the family members would positively give their consent to the eye donation.

Beard et al. (2002) found that families felt that the approaches were considerate, sensitive, compassionate, professional, sympathetic, down to earth, practical, caring, and factual. It may be argued that the findings of the dissertation study are related to the consent obtained in the available literature. The considerate, sensitive, and compassionate approach was used to pave the way for the eye bank coordinators to secure the consent of the family members they interacted with. Tissue donor family members believed that being able to donate tissue or organs gave them comfort during their grief (Hogan et al., 2014). Understanding how donor families cope with their loss and help others during this time through organ, eye, and tissue donation could help donor coordinators increase consents. The findings of Hogan et al. (2014) may also be related to the dissertation study because the consent given by the family members to the eye bank coordinators may have also been influenced by their desire to find comfort in the grieving process.

The experiences of the participants made them more cautious of their actions. Further, some participants also noted that not being able to read the reactions of the families also hindered their ability to have favorable response from the families. Hoy et al. (2011) examined the effects of a five-week online transplantation elective course on graduate nursing students. This study was conducted at the University of Alabama Huntsville, and Hoy et al. (2011) found a significant difference in the respondents' ability to discuss transplantation with friends and family. It may be argued that the negative experiences of the eye bank coordinators may be linked to their lack of trainings as proposed by Hoy et al. (2011). Consequently, for the negative experiences, all participants believed the key strategy was to constantly work to ensure they were communicating and conveying the correct information to the family members. Other emerging themes were coaching and collecting oneself back and knowing how to read the actions and reactions of families.

Speaking with a physician can be a positive predictor toward donation (Zheng et al., 2012). The findings of the dissertation study are consistent with the findings of Zheng et al. (2012) because being able to talk to a physician may have changed the views of the grieving family members. Thus, the positive results of the eye donations may have been really influenced by the views of the physicians who handled the case of their loved ones. The eye bank coordinators explained how there were families who were more than willing to share and make their loved ones as donors. There were family members who could still react with compassion and kindness, despite the grief they are feeling. Thus, it can be said that securing the consent of the family members has also been affected by the willingness of the family members to help out and participate. The participants shared that there were family members who want to help others and wanted their deceased loved ones to leave a legacy in this world. The positive outlook of the family members definitely helped in facilitating the agreement of the family members to eye donations.

The perceived attitude of coordinators is an influential factor to the decision of family members. Rodrigue et al. (2006) found that if the family of the deceased perceived the requestor as more sensitive and compassionate, they were more likely to agree to donate. The dissertation findings were consistent with literature because the findings confirmed the importance of being able to demonstrate compassion. Zheng et al. (2012) theorized that early experiential learning has increased students’ confidence, motivation, and development of intellectual skills in many subjects; organ donation curriculum for medical students may improve health care providers' knowledge of and attitudes toward organ donation.

The second theme that emerged was the strategy of continuing with the usual protocol and ensuring the right information is conveyed to the family members, despite the initial positive response. Thus, the results of the responses to the second question merely emphasized the need to have the proper communication skills and training in approaching the grieving family members. Based on the findings of the study, it may also be argued that the negative experiences of the eye bank coordinators may have been triggered by their lack of formal and early education as to how consent must be secured from the grieving family members.

## Limitations of the Study

One of the limitations of the study pertains to the number of eye banks that participated in the dissertation study. It may be said that the limitation was political because not all eye banks were able to open the views of their eye bank coordinators for certain studies like the dissertation research. Many eye banks are reluctant to speak with other eye banks regarding the policies and procedures because they may be subject to scrutiny after being shown in studies. Another limitation of the study pertained to the recruitment of the participants. The investigator was unable to gauge how many people would be willing to participate from these eye banks. Despite the limitation in the sampling, the investigator was able to gain specific insights from the in-depth account of experiences provided by the participants. It bears noting that the type of research method used in this study also poses a limitation because the type of study involved emotional aspects, which may have limited the objectivity of the study. No standard procedure exists for interpreting the findings and research conclusions. The interpretations were just derived from the conclusions of the investigator based on the lived experiences of the participants. It can be noted that the results of the study were still trustworthy because the investigator used the process of bracketing, audit trail, and transcript review.

While conducting this research there were many barriers that this investigator encountered. The investigator had to make the assumption that the coordinator was willing to share negative experiences, difficulties discussing eye donation and the consent process with grieving families, and the coordinators own attitudes and beliefs regarding donation. Another limitation of the study pertained to the fact that the data collected were limited to the information given by the eye bank coordinators. Further, another limitation pertained to the lack of sufficient measure to determine the level of compassion showed by the eye bank coordinators. It should be noted that one of the effective characteristics was the compassion showed by the eye bank coordinators.

## Recommendations

Future researchers may explore a different research method. To give an example, a quantitative method may be used to determine with precision how the eye bank coordinators perform in securing the consent of the family members. Further, mixed methods may also be helpful to ensure that the accuracy of the results is present while giving the participants the ability to explain their perceptions and lived experiences. Future researchers may choose a larger sample to increase the generalizability of the results. Another recommendation is to change the research questions.

The participants’ experiences varied with the emphasis on working even harder to encourage more donor and achieve their goals accordingly. Future researchers may focus on the ways that may possibly encourage family members to agree to eye donations. During the interviews, the participants expressed how the positive experiences became their motivation to help and save more individuals in need of a transplant. Future research questions that may be explored may include the motivations of the family members in giving or not giving their consent to eye donation. Another possible topic of future research may then include the implications of the motivations and how these motivations actually affected the decision to give or not give their consent.

There were various stakeholders that the eye bank coordinators had to deal with. Organ donor coordinators have to deal with these family members, who are experiencing extreme emotions with the sudden death of a loved one. These organ coordinators are at the hospital and are able to build a rapport with the families for days prior to approaching the families for consent. Future researchers may primarily focus on the aspects of how the eye bank coordinators may be able to build rapport with hospitals and family members because building rapport may be seen as the social aspect to ensure that all the stakeholders will be benefited.

## Implications

The results of the study have a positive impact to social change because the eye banks across the country would benefit from the findings and information discovered by answering the research questions in this phenomenological research. Further, the eye bank executives would also gain insights from the lived experiences of the staff, including the eye bank coordinators, especially when the eye bank coordinators talk to the grieving families. Based on the experiences of the participants, the eye bank coordinators would be able to have new knowledge and techniques about how to approach the family members for eye donation to ensure the positive cooperation of the families. The traditional attitudes, experiences, beliefs, and knowledge of family members may be used and applied to future coordination for eye donations. In this way, future coordination for eye donations may be effectively facilitated. The personalities of the eye bank coordinators would also be improved. There would also be positive implication to research. As previously mentioned, only few researchers have focused on the perceptions and lived experiences of the eye bank coordinators. However, the literature review was enriched with an empirical basis, which can be used as starting point for future studies.

The theories used in this study would also be enhanced by the findings of the study. Through the findings of the study, using perceptions and experiences of eye bank coordinators, the theory of planned behavior and the self-perception theory may be explained within through an example within the field of communication, specifically for organ donations. Thus, there would be an empirical example in the field of organ donations, particularly eye donation, to the theories used in the study. Therefore, the findings of the study also have theoretical implications and significance in terms of expanding the scope of applicability of the theory of planned behavior and the self-perception theory.

In addition to the practical positive implications of the research, the research would also promote positive social change in the field of research. Future researchers would be able to develop other possible aspects of research pertaining to the business of eye banks with the findings of the dissertation study. Future researchers would also benefit because the findings have already developed a well-founded background on the lived experiences and perceptions of eye bank coordinators in obtaining the consent of family members who are grieving. Future researchers would benefit because the findings of the study may serve as a starting point in developing other aspects of study, such as securing the consent for other organs of the body. Further, the researchers would also be beneficial to literature because future researchers may be able to explore other methods because a phenomenological approach has already been conducted.

In addition to positive social changes brought to practice, research, and theory, the findings of the study would also be able to assist different institutions, such as tissue banks and eye banks, in the implementation of policies to train the eye bank coordinators in securing the consent for eye donation. Further, eye banks may also be able to offer a more effective training to the eye bank coordinators based on the findings of the study in which effective and ineffective techniques were based on the lived experiences and perceptions of the eye bank coordinators.

## Conclusion

The investigator dealt with the general problem of the difficulty to assess the family's progress in the grieving process when calling for eye donation consent. With the roles and responsibilities of eye bank coordinators, they were required to deal with families undergoing complex set of emotions of the family members. Calling families too soon after the death of a loved one may turn the families off from donating eyes for transplant. The investigator dealt with the lived experiences of the eye bank coordinators in seeking consent. The specific problem that was addressed in the study pertained to the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent are unknown.

The purpose of this phenomenological research was to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching the family members for their consent to the eye donation. To address the problem and to be able to achieve the purpose of this phenomenological study, the overarching research question, the investigator sought to answer the following question: What are the lived experiences of eye bank coordinators regarding requesting permission for eye donations from bereaved families? A phenomenological method was used to allow the participants to properly relay their lived experiences and perceptions.

To address the research question, the investigator used qualitative phenomenological research design in order to explore the perceptions and lived experiences of the participants. IPA studies are utilized to find the meaning of the lived experiences of a particular group of people. In this particular study, the group of people shared the same experiences, and each shared different accounts of those experiences. This study was designed to delve into the phenomenon of the experiences of eye bank coordinators before, during, and after making a call to families to obtain consent for eye donation. Eye banks across the country would benefit from the information discovered through this phenomenological research. Also, the information gained from this research would help eye bank executives in understanding the experiences of staff, specifically eye bank coordinators, when talking to grieving families. The results of the study would contribute to positive social change as there were previously no sufficient research pertaining to the experiences of eye bank coordinators.

This investigator has successfully described the lived experiences of eye bank coordinators when approaching families to donate eyes of their loved one. The specific problem of the study was about the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent are unknown. The purpose of this phenomenological study was obtained as it was obvious that the investigator was able to explore and understand the lived experiences and perceptions of eye bank coordinators when approaching a family for eye donation consent. The information gained from this research would help develop a training program and ease the concerns of the coordinators when dealing with difficult families. The eye bank coordinators would have sufficient understanding of the ways to ensure the positive consent of the families. Also, the information gained would help future coordinators learn from these experiences.  It bears noting that an effective training program would help increase the number of donors in South Florida and increase the number of corneal transplants performed in the area.

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# Appendix A

## Proposed Interview Questions

**Background**

1. How long have you worked as an eye bank coordinator?
2. What previous experience do you have with talking to families?
3. What is your attitude toward organ, tissue and eye donation?

**Experience**

4. What being an eye bank coordinator mean to you?
5. What have been your experiences as an eye bank coordinator when asking permission for donation from the families?
    a. Positive experiences? Please cite examples.
    b. Negative experiences? Please cite examples.
6. Do these positive/negative experiences/situations affect your ability to approach families for eye consent?
    a. Do you get discouraged by negative families or do you get encouraged help them understand donation better to get their consent?
    b. Please explain how these positive/negative experiences/situations affect our ability to approach families for eye consent.
7. Please describe the feelings you experience when approaching families about the donation process?
8. How does the work define who you are as a person, overall?

9. What happens to your confidence level after having a negative experience with a family?
10. What happens to your confidence level after having a positive experience with a family?
11. How do you manage your stress while working?
12. How do you adjust your style of talking to families depending on their initial reaction to your request for donation?
    a. For families who welcome the possibility of donation?
    b. For families who are slightly hesitant to commit to donation?
    c. For families who are firm about the decision to decline?
13. What is the most rewarding aspect of your work?

# Appendix B

## Invitation to Participate for Executive Directors

Date: Month/Day/Year

Florida Lions Eye Bank
900 NW 17th St, 348
Miami, FL 33136

Dear Elizabeth Fout Caraza,

**Re: An Interpretive Phenomenological Analysis: Exploring the experiences of eye bank coordinators when approaching families of decedents for eye donation.**

The Interpretive Phenomenological Analysis: Exploring the experiences of eye bank coordinators when approaching families of decedents for eye donation study is a research is to fulfill my requirement for a Ph.D. in Health Sciences. This study is being conducted by me in conjunction with Nova Southeastern University.

The study aims to recruit 4 individuals (one from your organization) to participate in the study. Individuals that are being recruited are eye bank coordinators who speak with families to obtain consent for eye donation. Supporting this research will help me gain the meaning of the lived experiences of the coordinators before, during and after making a call to families. This research could also help the industry understand these experiences and help provide a training program and support for these individuals.

I understand that some people may have feel anxious about taking part in a research project. I appreciate that you and your staff are very busy, but please take time to consider this study. With your permission, I would contact your staff members to invite them to participate in the study. If you have any questions or concerns, please feel free to contact me. I very much hope you will lend your support to this valuable research.

Sincerely,

Concetta Triglia

# Appendix C

## Invitation to Participate for Eye Bank Coordinators

### Invitation to Participate in the Research Project Titled: An Interpretive Phenomenological Analysis: Exploring the Experiences of Eye Bank Coordinators when Approaching Families of Decedents for Eye Donation

Dear Eye Bank Coordinator,

I am conducting interviews as part of a research study to increase our understanding of the lived experiences of eye bank coordinators before, during and after making phone calls to families to obtain consent for eye donation. As an eye bank staff member who speaks with families you are in an ideal position to give us valuable firsthand information from your own perspective.

There will be two phone interviews which are approximately 45-90 minutes and are very informal. We are simply trying to capture your thoughts and perspectives on being an eye bank coordinator. Your responses to the questions will be kept confidential. Each interview will be assigned a number code to help ensure that personal identifiers are not revealed during the analysis and write up of findings. There is no compensation for participating in this study. However, your participation will be a valuable addition to our research and findings could lead to greater understanding of your experiences when speaking with families.

If you are willing to participate, please sign the attached informed consent, and I will contact you to schedule the interview that works best for you. Also, you may choose the most comfortable place for you to conduct the interviews. If you have any questions, please do not hesitate to ask.

Sincerely,

Concetta Triglia

# Appendix D

## Informed Consent

### Consent Form for Participation in the Research Study Entitled: An Interpretive Phenomenological Analysis: Exploring the experiences of eye bank coordinators when approaching families of decedents for eye donation.

Funding Source: None.

IRB protocol #: XXXX

Principal investigator:

Concetta Triglia, MS
714 NE 10th St, 303
Hallandale Beach, FL 33020
954-494-6533

For questions/concerns about your research rights, contact:
Human Research Oversight Board (Institutional Review Board or IRB)
Nova Southeastern University
(954) 262-5369/Toll Free: 866-499-0790
IRB@nsu.nova.edu

**What is the study about?**

The goal of this research is to explore the lived experiences of the coordinators and to find commonality among those experiences. This research will also attempt to find meaning in their lived experiences. Currently, there is no research that examines the experiences of the eye bank coordinators before, during, and after making the phone call to the families. Ultimately, the information gained from this research may help eye banks develop a training program to help coordinators speak to families.

**Why are you asking me?**

The participants that will be included in the study will meet the following criteria: (1) is an employee of The Florida Lions Eye Bank, San Diego Eye Bank, Rocky Mountain Lions Eye Bank and Lions Eye Bank of Nebraska, (2) have been an eye bank coordinator who speaks to families for the purpose of obtaining consent for eye donation, for at least 12 months to ensure familiarity with the process, (3) have handled positive and negative responses from bereaved families of potential donors, (4) male or female, (5) any age, and (6) fluent in English.

**What will I be doing if I agree to be in the study?**

The participant will be participating in two interviews. The first one will be about 45-90 minutes in length. The second interview will be a follow up to the first interview. This will give the participant/researcher a chance to elaborate or clarify any topics from the first interview.

**Is there any audio or video recording?**

This research project will include audio recording of the phone interview. This audio recording will be available to be heard by the researcher and a transcription company. The following the IRB, any granting agencies and the dissertation chair or committee if necessary. The recording will be transcribed verbatim by a professional company. The recordings and transcriptions will be kept securely on my computer hard drive that is password protected. The recording will be kept for 36 months after the completion of the dissertation and destroyed after that time will be permanently deleted off the computer hard drive. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the researcher will try to limit access to the recording as described in this paragraph.

**What are the dangers to me?**

Risks for this research study are minimal. The interview process may cause you some discomfort when answering the questions.

If you have any questions about the research, your research rights, or have a research-related injury, please contact Concetta Triglia. You may also contact the IRB at the numbers indicated above with questions as to your research rights.

**Are there any benefits for taking part in this research study?**

There are no direct benefits for partaking in this research study.

**Will I get paid for being in the study? Will it cost me anything?**

There are no costs to you or payments made for participating in this study.

**How will you keep my information private?**

All information gathered from the interview will be kept completely confidential. The audio recordings and transcriptions of the recordings will be kept on my computer hard drive which is password protected. The computer will be kept in a filing cabinet that it is locked with a key. Also, all information gathered from the interview will not be shared with the Executive Directors of the Eye Banks. The information will be stored for a minimum of 36 month from the conclusion of the study. All information obtained in this study is strictly confidential unless disclosure is required by law. The IRB, regulatory agencies, the dissertation chair/thesis adviser may review research records.

**What if I do not want to participate or I want to leave the study?**

You have the right to leave this study at any time or refuse to participate. If you do decide to leave or you decide not to participate, you will not experience any penalty or loss of services you have a right to receive. If you choose to withdraw, any information collected about you **<u>before</u>** the date you leave the study will be kept in the research records for 36 months from the conclusion of the study and may be used as a part of the research.

**Other Considerations:**

If significant new information relating to the study becomes available, which may relate to your willingness to continue to participate, this information will be provided to you by the investigators.

**Voluntary Consent by Participant:**

By signing below, you indicate that

- ☐ this study has been explained to you
- ☐ you have read this document, or it has been read to you
- ☐ your questions about this research study have been answered
- ☐ you have been told that you may ask the researchers any study related questions in the future or contact them in the event of a research-related injury
- ☐ you have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- ☐ you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the study entitled: Exploring the experiences of eye bank coordinators when approaching families of decedents for eye donation.

Participant's Signature: ______________________________________ Date: ________________

Participant's Name: ________________________________________ Date: ________________

Signature of Person Obtaining Consent: ______________________________________________

Date: __________________________________