To the Graduate Council:

I am submitting herewith a thesis written by Rebecca Venable Ferguson entitled "The Effect of a Puppet Presentation to Teenagers on Attitudes and Family Communication." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Child and Family Studies.

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The Effect of a Puppet Presentation to Teenagers on Attitudes and Family Communication Regarding Organ Donation

A Thesis

Presented for the

Master of Science

Degree

The University of Tennessee, Knoxville

Rebecca Venable Ferguson

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DEDICATION

This thesis is dedicated to my husband, Jim Ferguson, and our daughters, Emily and Jenny, whose encouragement, insight, support, and patience enabled me to focus on my academic endeavors in spite of the many hindrances that a "late in life" education brings to an already busy family.

I also dedicate my thesis to Margo Akerman for providing such a wonderful role model to all who view our program. She is a positive witness to the responsibility to and appreciation of the silent heroes--the givers of the "gifts of life."

ACKNOWLEDGMENTS

I would like to thank my major professor, Dr. Julia Malia, for her genuine interest and support during my research and thesis preparation. She was the spark that ignited my renewed interest in academia. She has the unique ability to pleasantly insist on perfectionism, while instilling this same desire in her students. I would also like to thank Dr. Greer Litton Fox for her quick eye and insightful thinking. She can identify problems and help find solutions while many are just opening the book. And finally, I want to thank Dr. Mitch Goldman. He is a true physician. His work is not just in healing the sick, but in helping the whole community to realize the joint effort required for "gifts of life." I truly appreciate his willingness to go beyond the sometimes rigid structures of the norm and welcome me into the arena of the operating room to witness a kidney transplant.

ABSTRACT

In this quasi-experimental design study an intervention of an interactive puppet program (Kids on the Block) was used to examine the effect it has on initiating and stimulating conversation about organ donation within families. It was also used to see if attitudes and knowledge of organ donation could be modified.

The sample population was from driver's education classes in five high schools in Knox County, Tennessee (4 public; 1 private religious). A total of 314 students between the ages of 15 and 17 ($n_{control}$ = 145; $n_{experimental}$ = 169) participated. A pre- and posttest were administered with the Kids on the Block" - Darryl's Gift" being the intervention. All groups were given the Tennessee Department of Safety handout, "Give Life to Your License."

The results sowed that the experimental group had a significant increase in the number of students who talked

to their families about organ donation (29% vs. 13.8%). Also students receiving the intervention differed significantly in attitude and knowledge change scores from the pre- and posttests.

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1. INTRODUCTION

Over the last 40 years, organ transplantation has evolved from the experimental stage to status as a recognized accepted treatment option for patients with life threatening end-stage organ disease (Fox, 1994). While many forms of transplantation now are done with impressive results, their very successes have created a problem that is a potential threat to transplant future: a critical shortage of donor organs (Spital, 1996; Dhooper, 1990; Smith, 1990).

Factors contributing to this shortage include: (a) an increased demand for organs, (b) an expanded base of recipient eligibility criteria, (c) successful safety measures and laws, and (d) a concern about AIDS (Caplan, 1994). Although there is a dire shortage of donor organs, hospital records reveal there is an adequate potential donor pool; it is the rate of refusal to donate that is the major impediment to the procurement process (Siminoff, Arnold, Caplan, Virnig, & Seltzer, 1995).

In the United States, the Uniform Anatomical Gift Act (UAGA) of 1968 gives all competent adults legal authority to decide whether they want to be organ donors or not, and doctors must honor decedents' wishes. However, many Americans never record their wishes, and, when they do, procurement organizations still ask the family of the deceased for consent. Thus, the need to obtain family consent has been identified as the major barrier to organ procurement (Spital, 1996).

Initially it was felt that the low number of available organs was a direct result of the medical profession's failure to ask (Smith, 1990; Prottas & Levine-Bratten, 1988). However, recent research has revealed that health care providers were asking; families were simply saying no (Siminoff et al., 1995). Other studies reveal the positive and preeminent role that prior education and family discussion play in a family's decision to say yes to organ donation (Pelletier, 1993), supporting the notion that the role of communication in

the decision-making process is essential. Prior communication concerning organ donation becomes a valuable resource to the family at the time when they are in the crisis of the tragic loss of a loved one and faced with the additional stressor event of having to make the decision of whether to become a donor family. Discussion of organ donation based on prior knowledge of the deceased member's wishes helps the family to establish, recognize, and clarify the reality of the death of the family member, moving the family closer to an acceptance of the death. Because there is a strong connection between (a) education about or discussion of organ donation and (b) a positive response (agreeing to donate) (Hall, Callender, Yeager, Barber, Dunston, & Pinn-Wiggins, 1991), the resource of prior discussion becomes not only a positive outlet to a family trying to manage stress during a crisis, at which time little seems positive, but it also results in increasing the number of available organs.

My personal involvement with the Kids on the Block organization began in 1985 with volunteer participation in a disabilities troupe that performed throughout the elementary schools in Knox County, Tennessee. This involvement led to my employment in 1989 by Child and Family Services, the supporting agency for Kids on the Block in Knoxville, Tennessee. In that same year, Kids on the Block was approached by Tennessee Donor Services and The University of Tennessee Medical Center of Knoxville to consider developing a program on the topic of organ donation and transplantation. Application was made to the national Kids on the Block organization; funding was approved and work began that same year.

Being a part of the research and development committee for the "The Gift of Life" program introduced me to both the topic of organ donation and a volunteer puppeteer, Margo Akerman, who was also a kidney recipient. We, along with the transplant coordinator at the area transplant center, Elaine Vuyosevich, became the

performing troupe for "The Gift of Life" and have represented the Kids on the Block on numerous occasions throughout the United States. Having both a working and a personal relationship with two individuals so intimately involved with transplants, I developed a keen awareness of the shortage of organs and curiosity concerning the decision-making process of donor families.

With the positive reception our "Gift of Life" troupe was receiving, not only in local classrooms, but also with adult audiences nationwide, I felt that we possessed a tool that demanded further research. Because of the visual and emotional impact the puppets have on an audience, I wondered if the program was making a significant difference in getting families to talk about organ donation, communication that can play a vital and positive role in a family's decision-making process should they ever be confronted with the dilemma that a tragic loss can precipitate. Therefore, the purpose of this study is to examine the effectiveness of an organ

donation educational program using puppetry in providing high school students information about organ donation and in stimulating them to discuss organ donation with their families.

2. REVIEW OF THE LITERATURE

Research in the field of organ transplantation has evolved over the last forty years to reflect the successes in this highly technical, biologically based therapy for people whose lives are threatened with end-stage organ disease (Fox, 1994). The essential genetic link between donor and recipient was realized early on in the attempts to transplant, and so followed the advent and continued development of improved immunosuppression therapy. Surgical procedures likewise have been mastered to the point of becoming routine (Starzl, 1994). Improvements in surgical techniques and chemotherapy together have expanded the age allowance for the recipients and broadened the realm of diseases for which transplantation is considered a viable treatment option (Smith, 1990). Many areas of transplantation have evolved to the point where they are covered by private insurance carriers and Medicare/Medicaid (Kutner, 1987). Although research continues to advance and refine transplantation

techniques and therapy, "high tech" medical issues are no longer the barrier they once were, preventing progress in the field. In fact, such technical progress has resulted in the emergence of a problem that renders all other successes irrelevant: organ shortage (Prottas & Levine-Bratten, 1988; Morris, Wilcox, & Frist, 1992; Smith, 1990; Spital, 1996).

There were 49,028 people on the waiting lists for transplant surgery in the United States as of October 9, 1996 (United Network for Organ Sharing, personal communication, October 16, 1996). One donor can yield more than one available organ for transplantation. In 1995, there were 5,300 cadaveric donors and 3,000 living donors, yielding nearly 20,000 transplants. (The term living donor normally denotes a living relative who donates a kidney to a patient. Because this situation represents an entirely different set of criteria, both in the selection and decision-making process, the present study does not focus on that area of transplantation.)

An average of nine people die every day waiting for an organ transplantation (United Network for Organ Sharing, personal communication, August 26, 1996). Only when the major impediment of organ shortage is resolved can progress continue. Thus, there has been a shift in research in recent years from one of a highly technical nature to one of a "low tech" nature: increasing organ supply or organ donation.

The Evolution of Organ Shortage

Early research efforts to identify reasons for the critically short supply of cadaveric organs began with numerous polls and retrospective studies, all of which revealed a discouraging paradox: "a shortage in the face of plenty" (Merz, 1985). Caplan (1994) cited the major factors contributing to the organ shortage to be: (a) an increased demand for organs due to the success rate and thus an increase in transplant centers; (b) more people eligible for transplants due to the expanded age limit and the lessening of limits on diseases like diabetes;

(c) successful safety measures such as seatbelts, speed limits, and helmet use, thus decreasing the supply of organs; and (d) concern with AIDS. From these factors, strategies surfaced to attempt to expand the number of potential donors. Currently, determination of one being a potential donor is based upon medical criteria usually involving sudden, unexpected trauma and brain injury, leading to brain death (Fulton, Fulton, & Simmons, 1987). Klassen and Klassen (1996) suggested increasing the potential donor pool by: (a) expanding the definition of eligible donors, (b) identifying nonhuman sources of organs, (c) dividing single organs among multiple recipients, and (d) taking action to decrease family refusals to donate. However, the solution is not to be found in expanding the number of potential donors. In spite of the shortage, there still exists a sufficient pool of potential donors. Although one normally considers potential donors to come principally from trauma deaths, one study identifies nontrauma donors as a significant,

yet overlooked, source. A review of 1,293 nontrauma deaths at Vanderbilt Medical Center during a 31-month period revealed that 0.77% of those deaths would have qualified as potential donors. While this seems to be an extremely small, insignificant number, when extrapolated to cover all nontrauma deaths in the United States in one year, the number would meet the current demands for all heart and liver transplants and 14% of the kidney transplants (Morris, Wilcox, Noreuil, & Frist, 1990).

Because there is a sufficient number of potential donor deaths, research emphasis recently has been placed on the techniques used in procuring such organs. Such efforts would be less expensive and perhaps easier to solve than the medical and scientific dilemmas presented by other procurement techniques such as nonhuman organs and dividing single organs between several recipients (Council on Ethical and Judicial Affairs, 1994; Younger & Arnold, 1993; Siminoff et al., 1995). Yet the efficiency of the procurement system continues to yield numbers far

short of the need, and potentially preventable deaths occur daily due to this "shortage in the face of plenty."

A 1993 Gallop poll revealed that 95% of Americans are aware of transplantation and 55% said they would be willing to grant formal permission to donate their organs after death, yet only 28% had actually taken such steps (via organ donor cards or statement to the family or medical profession) (Veatch & Pitt, 1995). Similar results had been found in a 1990 Gallop poll, which indicated that the general public supported the idea of donating their own organs (60%) or those of their relatives (80%), but only 15-20% of the potential donor pool actually took steps to become donors (signed donor card, or statement to family). Even as early as 1985, 75% of Americans approved of organ donation, but only 17% had signed donor cards (Geva & Weinman, 1995). A nationwide telephone survey conducted by a subcommittee of United Network for Organ Sharing (UNOS) to assess public attitudes toward donation also found that 79% of

the 800 participants had no objections to organ donation but only 36% claimed to have taken active steps to become an organ donor (i.e., signed a donor card or statement to family or medical profession) (Dittur, Hogan, Thukral, McGaw, & Alexander, 1991).

The paradox of a favorable view of donation and a shortage of organs actually donated has led researchers to look for the missing link in the procurement procedure. Because of the apparent willingness of people to donate, it first seemed logical to assume that failure to get organs happened at the point of request for the organs. Thus, the medical or health profession was thought to be the reason for the discrepancy (Prottas & Levine-Bratten, 1988; Gaber, Hall, & Britt, 1990). Pelletier's (1993) retrospective study of the needs of family members of potential organ donors supported this identification of health professionals as the "weakest link" in the donation process. Since most donors' deaths have been unexpected, resulting from head injuries

sustained in some type of trauma, most donor families have experienced the environment of an Intensive Care Unit (ICU). Pelletier's sample population was from this group of families. While many of the donor families' needs are similar to other families with members in the ICU, Pelletier identified some differing needs--particularly in a shift from staff concern for the patient to staff concern for the family. There was also a shift of emotional support for the patient over to the family. The findings indicated a need for recognition of the shift of concern and emotional support. Failure of medical professionals to ask the family to donate was related to a fear of intruding on the family at such a difficult time in their grieving process. However, families noted that they wanted to be asked and were later disappointed if such an offer had not been made.

Such opinion polls and surveys led to two key conclusions: 1) Most families will donate if asked, and 2) most health care teams don't bother to ask (Colburn,

1995). These conclusions led to the enactment of various required request laws in all fifty states. Required request laws provide additional support to the Uniform Anatomical Gift Act (UAGA) of 1968. The UAGA gives people of sound mind aged 18 or older and their families the opportunity to donate, at time of death, all or part of their bodies for any medical purpose. When the deceased person and family members disagree about the donation, the deceased person's wishes should be respected (Sadler, Sadler, & Stason, 1968). During the '80s, required request laws became requirements for federal Medicare reimbursement and hospital accreditation, making it standard hospital policy throughout the United States (Siminoff et al., 1995).

It was anticipated that compliance with required request laws would result in an increase in the organ supply, but this was not the case. In their assessment of the impact of required request laws, Gaber et al. (1990) found a temporary increase in donors followed by a

drop in the numbers. Questions were raised concerning the possibility of relaxation of hospital implementation and the inability to check compliance. But through the development of a screening protocol, it was found that physicians were largely in compliance with the required request laws (Morris et al., 1990). It also was suggested that required request laws' lack of effectiveness was due to the health profession's fear of legal liability (Siminoff et al., 1995), particularly in the area of requesting permission from the next of kin. Although the UAGA and required request laws support a hospital's and physician's rights to adhere to the deceased's wishes when known, most transplant surgeons will not remove organs without the living relatives' permission, and half of potential donations are refused by next of kin when requested in a hospital setting (Klassen & Klassen, 1996). A study also indicated that physicians and organ procurement professionals do not override next of kin refusal because of concern for the grieving family and

fear that their legal right to abide by the deceased's opposing request would be perceived publicly as a forceful tactic (Harris, Jasper, Lee, & Miller, 1991).

As a result, it is now generally felt that health providers are doing an adequate job of asking families; families are simply refusing (Siminoff et al., 1995). It has been suggested by Merz (1985) and Geva and Weinman (1995) that the way in which a family is asked affects the refusal rate, particularly in cases where the deceased's wishes are unknown. Interestingly, it was noted by Harris et al. (1991) and Pearson, Bazeley, Spencer-Plane, Chapman, and Robertson (1995), in separate studies--one hypothetical, the other a retrospective study of 69 potential donor families--that the primary factor considered by the family when making a decision to donate is the wish of the deceased, particularly if it has been in writing or clearly stated verbally to the next of kin. If those wishes were known, the family abided by them 100% of the time, <u>even when they were</u>

different from their own. When the deceased wishes are not clearly stated, the personal attitudes of the living relatives become more important, along with the timing and style of the professional making the request.

A random sample telephone survey of 750 adults supported the universal approval of organ donation, yet only 50% said they would donate their relative's organs if they did not know the relative's preference (Prottas & Bratten-Levine, 1991), indicating that families are refusing donation at least 50% of the time when there has been no communication concerning organ donation prior to the member's death.

The impotence of the required request laws and the realization of the importance of knowing how the deceased feels toward organ donation have yielded much debate and support for two other solutions to the organ shortage dilemma: presumed consent and mandated choice. Although it is argued that the legal and literal meaning of presumed consent contrasts from the general

interpretation (Veatch & Pitt, 1995), it is usually understood to mean that one assumes that people consent to be donors unless they or their families register an objection, otherwise known as "opting out" (Council of Ethical and Judicial Affairs, 1994). Veatch and Pitt (1995) compared the issue of organ donor presumed consent to the presumption of consent for treatment in an emergency room when the patient is rendered incapable of consent due to injury or illness. Aside from cases in which the family is a member of certain small groups such as Jehovah's Witnesses or Christian Scientists, there is general agreement that presumption of treatment would be unanimous and thus valid.

However, presumed consent with organ donation should not be similarly assumed. After examining the people who either have said that they would probably donate their organs (55%) or have actually signed a donor card (28%), there remains about 20% of the population surveyed who do not want to donate. Thus, a presumption of consent would

be in error because it probably would be contrary to the wishes of the deceased about 20% of the time. Also called into question is the speculative style of these surveys. Perhaps it is too difficult for people to imagine themselves in a hypothetical situation of the donor family to accurately imagine their own decision. Therefore, they probably err on the "agree to donate" side when responding to the hypothetical situation. Yet, in the actual situation, families will err on the side of refusal when they do not know the deceased's wishes. Veatch and Pitt (1995) further speculated that "opting out" takes active participation, and the likelihood of someone making the effort to register a refusal would render the presumption of consent even more erroneous. Both of the previously mentioned studies, along with Merz's (1985) study of the organ procurement problem, noted numerous other nations where presumed consent laws have been established but found to be basically

ineffectual due to traditional values dictating that the family be consulted prior to organ removal.

Because family consent continues to be seen as the major determinant--an impediment--of organ procurement, mandated choice has emerged as an alternative to reducing the high refusal rate among families. It is designed to remove the family from the consent process and return the control to the individual by mandating that all adults record their wishes concerning donation. This could be accomplished at the time of driver's license application or on tax returns. One would have the option of changing the decision by a written directive. The decision would be binding and could not be overridden by the family (Spital, 1996; Veatch, 1991).

This process of mandated choice would not include registering children, a population that includes a large number of potential donors. The good health of most children, who represent a disproportionately large percentage of the victims of trauma deaths, makes them

particularly good donors. In a review of pediatric deaths (aged 1 to 16 years) over a 31-month period at a university hospital, it was extrapolated that a significant percentage of the 20,000 children who die each year in the United States are eligible donors. If less than 10% of those eligible actually became donors, the number of organs that would be made available would be 6 times the current demand for kidneys, 7 times the demand for livers, and 38 times the demand for hearts (Morris et al., 1992).

The chance of passing mandated choice legislation and implementing such a program currently are not feasible. The burden of developing a centralized registration system, the absence of children from the registry (they represent a large supplier group for donated organs--27%), and the hesitancy of people to deal with the underlying subject of death forces a closer examination of the problem of families' high rates of refusal (Klassen & Klassen, 1996). While there are

stumbling blocks on every avenue explored, there exists a common underlying suspect for family refusal in all studies and surveys, whether they are retrospective, hypothetical or based on telephone random samples of the population: a lack of family education and communication (Morris et al., 1992; Merz, 1985; Harris et al., 1991; René, Viera, Siles, & Daniels, 1995; Siminoff et al., 1995; Pelletier, 1993; Pearson et al., 1995; Fulton et al., 1987).

Results from the National Tissue and Organ Procurement Study (Siminoff et al., 1995) noted the need for education of both health care professionals and the general population. Research has shown that the health professionals do ask, but the problem might be in how they ask and who does the asking (Gaber et al., 1990; Merz, 1985; Siminoff et al., 1995; Pearson et al., 1995; Fulton et al., 1987). In each of these studies, willingness of the family to donate was associated with the type of health care provider involved in making the

request. When a medical social worker or clergy member was involved with the request the success rate was 66%, as compared to 51.1% when it was other types of health care providers. Health care professionals who received formal training about donation were more likely to ask families to donate but were found to be no more successful in obtaining consent than those with no formal training (Siminoff et al., 1995).

The conclusion is that greater emphasis on education should be in the arena of the general population. When a family has talked about organ donation prior to the death of a family member, the likelihood of donation increases dramatically. Public awareness and education get families to talk. Fulton et al.'s,(1987) retrospective study of relatives of cadaveric donors cited several instances where the families' recollections of previous conversations with the deceased clearly facilitated decisions to donate. In a survey of families of brain-dead patients in South Wales (Pearson et al., 1995), it

was found that the most important factors in the decisions to donate were : 1) prior discussion with the deceased by the next of kin, 2) prior knowledge of brain death, and 3) knowing the wishes of the deceased. If one has discussed organ donation in the family (#1), then the chances are good that the wishes of the deceased will be known (#3). An important further finding in the same study revealed that if a family had discussed organ donation previously, then the family often approached the doctor before the subject was raised to them.

Education is suggested to be one of the more important underlying factors contributing to lower numbers of family refusals in pediatric donations. The age of most of the parents of the children in Morris et al.'s (1992) study of the pediatric donor pool was between 30 and 39. This represents a cohort group that grew up with the flourishing field of organ donation and, hence, are more likely to be knowledgeable about the topic. Also included in the factors for lower refusal

rates in this group are (a) personal identification with other parents whose children face probable death without a transplant and (b) parent versus family responsibility for decision making. When the responsibility for the decision rests with the extended family (when the donor is an adult), a path of least resistance among the many members usually results in a refusal. But when children are the potential donors, the decision is often made by the parents alone and the donation rate increases (Morris et al., 1992).

Another tool appearing to have an effect on public awareness and education is organ donor cards. Several states have instituted aggressive campaigns to influence people to carry signed donor cards. While discovery of a donor card on the body of the deceased sends a definite and helpful message to the family needing to make a decision, the main success of donor cards is not that they surface at the hospital at the time of someone's death but rather that they often generate discussion of

organ donation with family members at the time of signing and witnessing the card (Merz, 1985).

Minority status presents an additional barrier in alleviating the organ shortage problem, particularly in the African-American community. Family refusal rate among all minority groups is 80% (René et al., 1995). With the incidence of end-stage renal disease being seventeen times greater for African-Americans than the general U.S. population, the higher rate of refusal has even graver significance. Thirty-four percent of the dialysis population and 30% of the people on the national waiting list for a kidney are African Americans. Yet African Americans comprise only 12% of the U.S. population and only 8.8% of the donor pool. Although it is possible to have interracial transplants, there is a much better organ acceptance rate if the organs are race matched, due to race-based antigens. Because the need for kidneys is much greater and the pool of donors is much smaller among African Americans, this results in an

even greater shortage for this group, and often a less than optimal organ match is made in the effort to save a life--often leading to eventual organ rejection and the need for another transplant. Survival rate of transplants is 10-20% lower in African Americans for this reason (Davidson & Devney, 1991).

In the spring of 1996, NBC's nightly news showed a poignant scene of baseball great, Rob Carew, holding his dying teenage daughter, for whom a bone marrow match could not be found. It was an emotionally packed reminder to the public of how serious and critical the organ shortage problem is to this specific population.

Education and Communication Efforts

Education can play a tremendous role in improving the statistics of organ donation in the U.S. From 1982-1989, a grassroots, volunteer type educational program in Washington, D.C., resulted in a 30-fold increase in African Americans signing donor cards (from 25 to 750 per month) (Hall et al., 1991). This one-on-one interview

program yielded 100% signed donor cards, when 90% initially were unwilling.

If public awareness and education efforts can increase and continue to be successful, there will be less pressure or strain on the health care professionals. In other words, education of the individual to talk to his/her family will reduce or supersede the efforts needed by the health care professionals to introduce or persuade the family to donate organs at a time when stress in the family is at its height. The health professional's job then becomes one of support, instead of intrusion. Doctors can focus on providing the family with the tools necessary to put into action a final request of the deceased. A skilled health care person, knowing when and how to present organ donation, becomes an advocate for the family and an initiator of a part of the healing process (Tennessee Donor Services, 1990).

The value of education and awareness efforts to promote communicating to family members one's wishes

concerning organ donation can be illustrated theoretically on two levels using the conceptual work of first Reuben Hill (1958) and then McCubbin and Patterson (1982). Both of these works contribute relevant elements to a discussion of family stress processes in response to a stressor event such as the death of a member (Boss, 1988). McHenry and Price (1994) describe a stressor event as "an occurrence that provokes a variable amount of change in the family system" (p. 6). They further classify stressor events as being either normative or nonnormative. Normative stressor events are described as transitions that are predictable parts of the normal family life cycle (e.g., birth, marriage, a member starting school, retirement, death of an older member) and are usually short in duration. Nonnormative stressor events are not predictable; they are unexpected and often involve some type of disaster (McKenry & Price, 1994).

It seems reasonable to assume that the majority of trauma deaths can be classified as nonnormative stressor

events for the surviving families. Using Hill's model (Figure 1), one can identify the role of prior communication about organ donation as a resource (Factor B) to the family during the nonnormative stressor event (Factor A) of a member's sudden, traumatic death. The family's perception of the event (Factor C) interacts with Factors A and B to produce Factor X (the level or degree of stress or crisis that the family ultimately experiences). In other words, how a family reacts to the trauma death of a family member (the family's degree of stress) is affected by the knowledge (a vital resource) of how the deceased felt toward organ donation. As noted earlier, numerous studies have found that knowledge of the deceased's wishes in large part determined the donation decision for the family and helped in the grieving process as the affirmation of fulfilling a last request for the loved one. As one person stated, "It was the only way we could bring something good out of something terrible" (Tennessee Donor Services, 1990 p4).

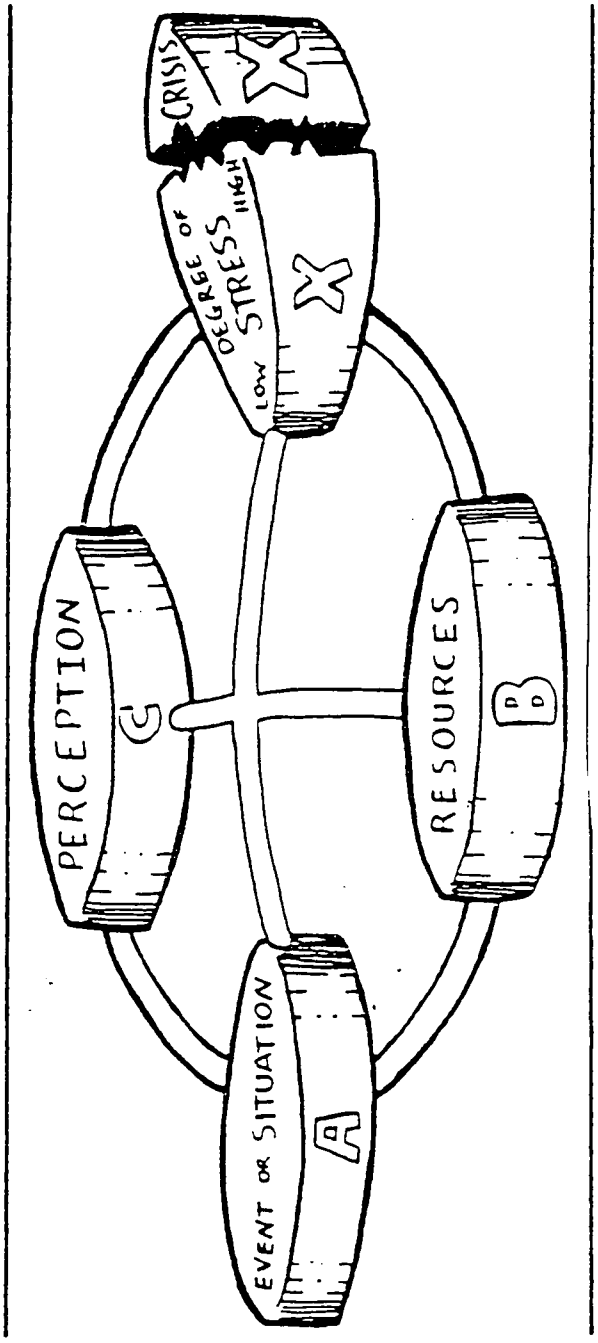

Figure 1. The ABC-X Family Stress Model (Hill, 1958)

McCubbin and Patterson (1982) recognized the role of postcrisis or poststress factors in a family's adaptation to stress and enhanced Hill's ABC-X model to include this extension of the framework (Figure 2). Their Double ABC-X model allows for the inclusion of multiple aspects involved with a family's attempt to manage a stressor event. Examples of pileup of events in the case of the initial trauma death stressor event would be (a) gaining information to understand the idea of brain death, (b) listening to the organ request from the procurement agency, (c) initiating a meeting with other family members to make a decision whether to donate, and (d) realizing that transplantation interrupts the customary accepted practices surrounding death by prolonging the period of distinction between life and death (Fulton et al., 1987). The decision to donate brings with it a different set of criteria surrounding the event of death. Our society traditionally has defined and accepted death as a "moment" in time, whereas brain death suggests more

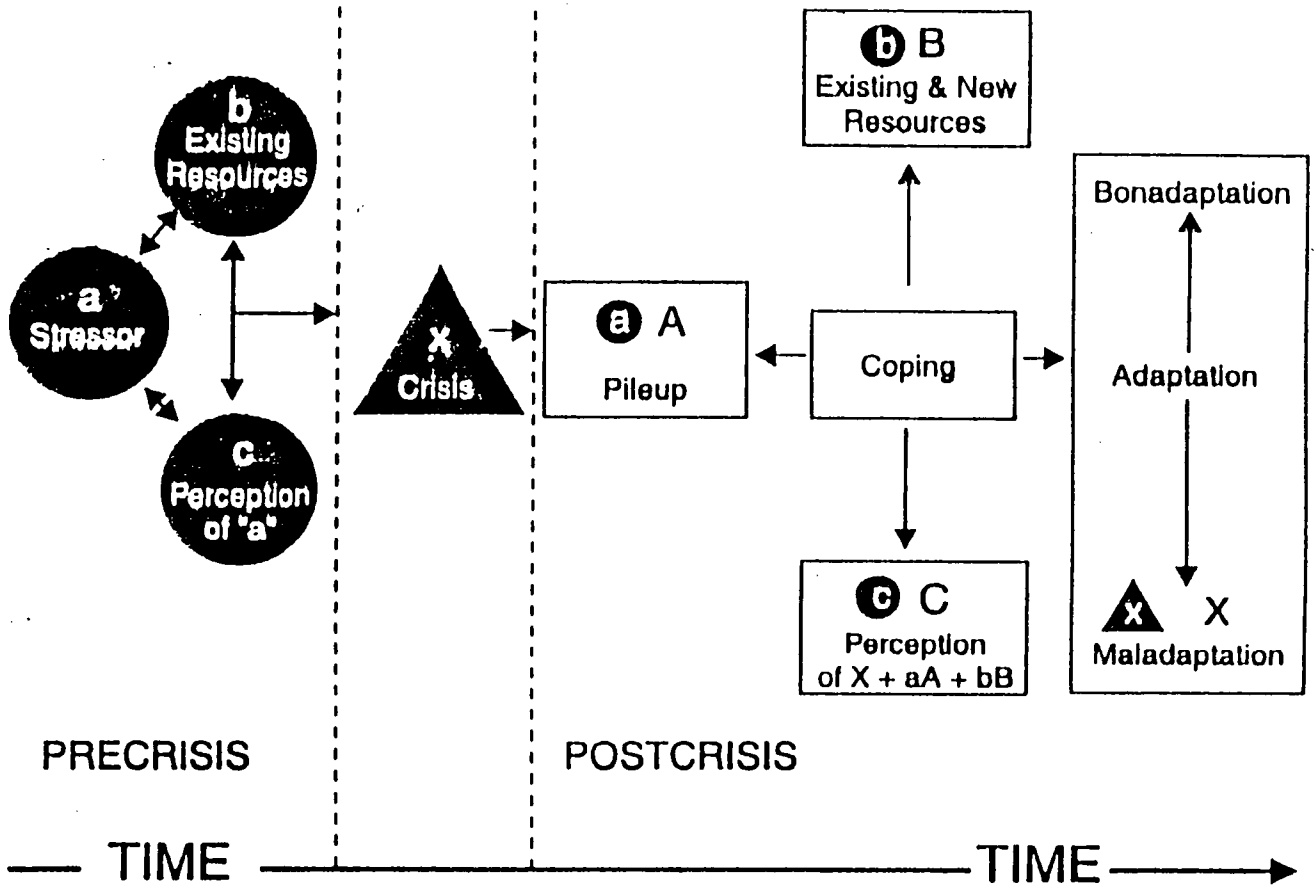

Figure 2. The Double ABC-X Family Stress Model
(McCubbin & Patterson, 1982)

of a process. Patients are "kept alive" on respirators and by chemical means in order to keep the organs in a viable condition for transplantation. Machines are not "unplugged" until during or after surgical removal of the organs. Therefore, the family "parts" with the victim before he or she is actually dead. This process can give a false question of hope to the family while extending the denial stage of death.

All of these additional stressor events are affected by the resources and perceptions that all the participants in the family unit bring to the decision-making process. How the family copes with each event is again largely determined by the level of knowledge and awareness members have about organ donation in general and the deceased's personal feelings toward it, all of which could be determined through prior education and communication. However, instead of serving as a resource, lack of such information becomes another stressor event in and of itself. Often families follow

the path of least resistance at such a stressful time and refuse to donate, only to regret the decision later when some of the stress has subsided. One of the driver's education teachers whose class participated in this study shared the story of such a family tragedy with me. The teacher's sister came to him two weeks following the sudden death of her son in an auto accident regretting that she had not donated her son's organs, yet also realizing that such a decision at the time of his death was too stressful to attempt. The regret was not so much that she had refused to donate, but more that her refusal was made based on being uninformed: Now that some of the stress had subsided, she felt that she had missed the only opportunity to bring something good out of something terribly bad. Although painful, the teacher's story was an excellent example he could give to his high school students of the importance of prior communication.

Additional recognition of the importance of prior discussion about organ donation among the family is found

in the ultimate level of adaptation, the family stress process outcome variable in the Double ABC-X model. Many families describe their decisions to donate as a help in the healing process. This outcome benefit results from the utilization of appropriate resources prior to and/or during the coping process.

It is important to mention that although research studies have shown that many families experience a feeling of altruism in their decision to donate and most families' experiences with donation are positive, it is not my intent to suggest that only a positive decision merits an evaluation of bonadaptation (as opposed to maladaptation) in coping with a trauma death. The power of the resource is in knowing the deceased's feelings concerning organ donation, whether those feelings are positive or negative, so that the family ultimately knows they are fulfilling the deceased's true wishes. The challenge comes in finding the appropriate tools with

which to initiate and stimulate communication in families.

Puppetry and Communication

Puppetry has long been associated with creating a medium for communication in a nonthreatening environment (Rickey, 1983). Puppets have been particularly useful in developing communication skills with children. In the area of nondirective counseling, puppets have been used to help meet the educational and emotional needs of adolescents (Egge, Marks, & McEvers, 1987). Because I have worked with an international interactive puppetry group, Kids on the Block, for over ten years, I have experienced first hand the effect puppets have in instilling understanding, knowledge, and sensitivity in audiences of all ages.

Several studies evaluating the level of learning and retention of the Kids on the Block disabilities programs have found them to be effective. Grider's 1985 study (as cited in Kids on the Block, 1996) used the Kids on the

Block as the intervention in her experimental-design doctoral thesis project to examine whether fifth- and sixth-grade students' attitudes toward the handicapped could be modified. She found that the intervention significantly affected the students' attitudes toward the handicapped and that the effect was maintained over time. Three other studies, Haugland (1986), Pendzick (1983), and Powell (1985) have found similar significant results (as cited in Kids on the Block, 1996).

In their evaluation of a puppet program designed to teach South African adults about HIV infection, Skinner, Metcalf, Seager, de Swardt, and Laubscher (1991) found that puppets were a good medium for overcoming racial and cultural barriers. They also found them to be effective and nonthreatening avenues for dealing on both the cognitive and emotional levels of a sensitive issue. Skinner et al.'s (1991) study was particularly relevant to mine because of both the use of adult audiences and the racial factor. It lent support to puppet acceptance

by older youth (teenagers in driver's education classes) and underscored the needs for racial inclusion in programs designed to reach the general population. The Kids on the Block "Gift of Life - Darryl's Gift" program centers on an African-American family's way of coping with the trauma death of a child and the ultimate decision to donate his organs.

Rationale

The critical need for organs, the identified reason for the shortage (lack of communication about organ donation within families), and the tool to provide better communication (puppetry) to an age where knowledge of such a topic is both timely and of personal interest (teenage driving age) led me to implement a pilot program with driver's education classes in area high schools and design a research project to evaluate its effectiveness. I hypothesize that, using no other prompting such as knowledge of a posttest, the impact of the program alone will be enough to make students go home and initiate a

conversation about organ donation with their families. The future ramification of such communication would be the role that particular conversation would play as a positive resource should the family experience a nonnormative stressor event in the trauma death of a family member. I also hypothesize that exposure to the program will result in a significant positive change in students' knowledge and attitudes regarding organ transplantation.

3. METHOD

The current study employed a quasi-experimental design (pre- and posttest) using quantitative data collection and analysis to examine whether high school driver's education students were influenced by an educational puppetry program (intervention) to talk to their families about organ donation. Attitudes toward and knowledge of organ donation also were evaluated to see if there was a change in students' responses following the intervention. Because of the nature of the intervention, there was a difference in the amount of time spent with the two groups.

Sample

All of the participants were between the ages of fifteen and seventeen and attending driver's education classes in one of five high schools in Knoxville, Tennessee, during the spring semester of 1996. Four of the high schools were a part of the Knox County Public Education System. The fifth was a private religious

school. All driver's education classes in Knox County public high schools were invited to participate through a personal letter to the driver's education teachers (see Appendix A), with a follow-up call to further explain the study and recruit participants. (Note: The private school was self-recruited because the driver's education instructor there also taught at one of the public schools and, therefore, received the letter.) Timing was critical in the process of participant selection because the Knox County system had just undergone a major change in its scheduling format and getting into the classroom before the students were assigned to road driving left a very small "window of opportunity."

The reason for targeting this age group is two-fold. Unfortunately, one of the largest pools of potential donor candidates is made up of people between the ages of 16 and 25 due to this group's higher occurrences of driving fatalities. And the relative well health of these young people prior to the accidents makes them good

potential donors. The Tennessee Department of Safety actively participates in the Organ Donor Label program for new and renewed driver licenses. Therefore, the driver's education classroom is an appropriate environment for such awareness building. The second reason for targeting this age group is not particularly age-specific, but rather environment-specific. The classroom provides a broad spectrum of the targeted population. Considering our hopes of reaching a broader spectrum of the general population via communication through families, this group was deemed appropriate.

Geographically, all parts of Knox County were represented except for the eastern part. According to Knox County School's Federal Programs Evaluator for Title I, Alan Cheatham (personal communication, October 4, 1996), the participating schools were representative of the high school population throughout Knox County as far as gender, racial, and socioeconomic distribution factors were concerned. However, the experimental schools had a

higher ranking as far as percentage of African Americans (15.4% and 7.7% versus 5.1% and 3.8% for the control schools) and the percentage of students on free or reduced lunch (29.81% and 24.98% versus 11.14% and 3.67%) as indicators of socioeconomic level. The two control schools scored above average on the Tennessee Comprehensive Assessment Program tests, while the two experimental schools' scores were average to slightly below average on these tests.

Because human subjects under the age of eighteen were used in the study, approval of Form B by the Institutional Review Board was required (see Appendix B for the body of Form B without attachments, which are in other appendixes). Due to the greater concerns considered when minors are subjects of research, classification of participants by gender and race were eliminated. Also, a waiver was requested to not require parental permission for each student to participate. Giving information to the parent about the study could

have jeopardized the main objective of the research (to measure the effect the program has on family communication about organ donation). Because the study (a) involved no more than minimal risk, (b) was with older children, (c) was for the purpose of evaluating an approved school curriculum tool (Kids on the Block), and (d) had appropriate mechanisms for protecting the anonymity of the participants, the waiver was granted.

The sample consisted of 314 students between the ages of 15 and 17 ($n_{control}$ = 145; $n_{experimental}$ = 169). The experimental groups were selected by virtue of being the first three schools that could be scheduled for a performance, with the remaining two becoming the control groups. An instructor in one of the experimental groups also taught driver education at a private, religious school in Knox County and asked if that class could be included; permission was given--resulting in a greater number of students in the experimental group.

Instruments

Likert-type pre- and posttests were developed by the researchers with the help of Tennessee Donor Services and The Greater Knoxville Kids on the Block, using twenty attitudinal and/or general knowledge statements about organ transplantation. Also, five yes/no questions were asked concerning personal involvement with organ donation (e.g., "I have a signed donor card" and "I have discussed organ donation with my family"). Five additional questions were included on the posttest of the experimental group asking specifically about the use of Kids on the Block as an effective and acceptable teaching tool in the high school classroom. (Both the pre- and posttests are found in Appendix C.)

Intervention

The intervention used with the experimental group was the segment called "Darryl's Gift" in the Kids on the Block "Gift of Life" program. (Appendix D contains a copy of the information flyer on this program.) The Kids on

the Block is an international program developed in 1977 that uses interactive puppetry to help communicate with children on topics of a sensitive nature, such as disabilities, abuse, divorce, AIDS, substance abuse, and, now, organ donor awareness. Its goal is to educate and instill an awareness in the audiences through the use of very large puppets performing in the Japanese style of puppetry called bunraku. In performing bunraku puppetry, the puppeteer is on stage with the puppet and in full view of the audience. The puppeteer wears black clothing and develops a technique of shadowing the puppet. An experienced puppeteer often goes unnoticed by the audience, yet is available to see and communicate (via the puppet character) with the audience for the important interactive segment of the program. Research studying the Kids on the Block and other styles of puppetry has shown that puppets are received and accepted by audiences of all ages, but particularly with younger children (Egge et al., 1987). Although realizing that the puppet is not

"real," audience members are able to temporarily detach themselves from that reality and actually relate and communicate with the characters. This provides an excellent environment for controlling and directing a focus for addressing a specific topic without requiring too personal or intrusive an invasion of the audience. Many of the Kids on the Block program topics, including "The Gift of Life," have been a part of the Knox County school curricula for over ten years, but none have ever been used in the high school classroom environment before this study.

In 1991, I had the opportunity and privilege of working with the national company in developing the program used in this research ("The Gift of Life"). The program took approximately a year to research, write, and field test. Like all Kids on the Block programs, its format includes scripted segments followed by a question-and-answer time. The "Darryl's Gift" segment concerns a family's decision to become a donor family after their

fifteen-year-old son is declared brain dead following a car accident. The scene takes place on Darryl's birthday and nearly two years since his death. Darryl's eleven-year-old sister, Mel, talks with her close friend, Michael, and answers many of his questions concerning the event, dispelling several myths and revealing some of the emotional aspects of the ordeal. Particular emphasis is placed on the role of communication in the family prior to the accident. Recalling a family conversation about a newspaper article involving a liver transplant, Mel relates how that prompted her family to have a discussion of how they each felt toward organ donation. At the time of Darryl's tragic death, recall of that conversation is what moved them to become a donor family, resulting in "something good coming from the tragedy." The audience then is given the opportunity to ask Mel questions. Both the scripted segment and the question-and-answer time are discussed through the eyes, mind, and experiences of an 11-year-old.

The Tennessee Department of Safety handout, "Give Life to Your License!" (Appendix E) also was used in this study but as an intervention given to both the control and experimental groups. This intervention was uniform across all groups in the study. This handout included information and answers to questions usually asked about organ donation, along with an organ donor card.

Data Collection

I personally collected all the data in the study. Upon my arrival at the classroom and introduction to the teachers, I reviewed my study with them, requesting that they not contaminate my research by putting any pressure on the students to talk to their parents about organ donation. I also would verify the date for my return to administer the posttest. After the signing of a statement of participation (see Appendix F) by the driver education instructors, I introduced my project to the students in each classroom with a statement of purpose concerning organ donation and transplantation as detailed

on the student consent sheet (see Appendix G). The entire consent sheet was reviewed, making sure everyone understood it. To insure students' anonymity while enabling pairing of the pre- and posttests, coding was required. The specific coding used the numerical day of the month of the participant's birthday followed by the last four digits of his/her driving permit number. Because most students had never been involved in such a procedure before and because correct pairing was critical to the integrity of the study, considerable time was given to make sure all the students understood how to appropriately code the tests. The pretest then was administered. Following completion of the pretest in the control groups, I gave the handout, "Give Life to Your License" to each student, thanked them for their participation, and left the school. In the experimental groups, upon completion of the pretest, the Kids on the Block "Gift of Life" puppet presentation was performed and discussed, closing with the distribution of the "Give

Life to Your License" handout. To justify the coding procedure the students were informed on the consent statement that there would be a posttest. But because one of the purposes of the study was to evaluate the effectiveness of the puppet presentation in initiating and stimulating family communication on the subject of organ donation, no emphasis was placed on my returning to administer a posttest.

The date of the return trip for the posttest was determined by the classroom instructor, due to the limiting constraints of classroom time, since all the classes were moving into the phase of being "out on the road" driving. A range of 3 to 7 days passed before I returned to administer the posttest. The posttest was identical to the pretest with the exception of an additional question asking if the student had talked to his/her family about organ donation since taking the pretest. The experimental group also was asked several

additional questions concerning the use of the puppets as a teaching tool in the high school classroom.

I went to the control high schools alone but, of course, was accompanied by my performing partner when doing the intervention with the experimental high school groups. I returned to administer the posttest to both the experimental and control groups alone. I then collected and paired all of the tests prior to coding the students' responses and entering the data into the computer for analysis.

Students were requested to not talk while taking the tests, and the request was honored except in my first control class. Being my first group, it was not "controlled" as well as I had intended, and several students started talking among themselves about various questions on the test. My appreciation for their interest in my topic superseded my need for their compliance with the limitations of the research situation. Before I knew it, the conversation had

stimulated heated discussion over which I felt I could not keep silent. It began with one student saying to her friend that they could not be organ donors because they both smoked. This statement was followed by a comment that she did not want to be a donor anyway because "when they take your organs out, they stuff you with wood." A student in front of them turned and tried to correct her, but she countered his correction with the "fact" that "once your organs were gone, you needed something to hold you up," thus, the need for the wood. He tried to explain the function of the skeletal system, but by then I felt that I had to intervene. I decided at that point to eliminate the class from the study, which freed me to try to salvage the whole field of organ transplantation by leading an educated discussion. The incident led to some positive communication and learning in the class, so all was not lost. But the episode did make me aware of the general public's lack of knowledge on the subject of organ donation and transplantation and underscored the

importance of the researcher maintaining control during questionnaire administration.

Data Analysis

The Statistical Program for the Social Sciences (SPSS), Version 6.0, was used to compile and analyze my data. Because neither the control nor the experimental groups were randomly selected and they did not contain the same number of participants, I was obligated to test the assumption of equal variances. Students' responses to the yes/no pretest question, "My family has discussed organ donation," was analyzed using Levene's independent samples test to ascertain the homogeneity of my two groups (control and experimental). The data supported the assumption of equal variances (i.e., I failed to reject the null hypothesis of equal variances). Because the groups were not systematically different regarding communication about organ donation in their families, I then could proceed with the analysis testing for pre- and

posttest differences between the groups regarding items asked on the tests (Huck, Cormier, & Bounds, 1974).

The yes/no posttest question: "My family has discussed organ donation since taking the pretest" was analyzed using Levene's independent samples t-test for significant difference between the two groups. Since the two groups (control and experimental) were found to be similar prior to the intervention (Levene's test), then any differences found in this analysis would be attributed to the intervention (Huck et al., 1974) with the assumption that all other factors were held equal (ceteris paribus). I also examined the effect that the pamphlet alone (i.e., without the puppet program) had on the control group by seeing how many control participants said "yes" to the posttest statement, "My family has discussed organ donation since taking the pre-test."

Shifts in responses to the attitudinal statements between the pre- and posttesting of the experimental group were analyzed using the paired t-test. Because I

had hypothesized that there would be a shift toward the favorable direction, a one-tailed test was used. Due to the large sample size, any change found to be significant was then examined to determine if that statistical difference was important (Norusis, 1988). In other words, because I had a large sample size, there was the danger that small differences between the groups may be statistically significant and yet not of any practical importance. And it is up to the researcher to determine if such differences are of practical importance.

I also looked at the number of new family discussions the intervention may have generated. This was determined by examining the number of experimental participants who said "no" to the pretest statement, "My family has discussed organ donation", and then said "yes" to the posttest statement, "My family has discussed organ donation since taking the pretest."

Finally, because I wanted to know whether the brochure alone had any impact, I examined the number of

control participants who said "yes" to the same posttest statement, after saying "no" to the pretest statement, "My family has discussed organ donation."

4. RESULTS

Testing the Assumption of Equal Variance

Table 1 shows the results of the Levene's test for independent samples (pretest), supporting the assumption that no difference existed between the two groups of participants (F= 1.785, df = 2/296, p > .05) at the outset of the study. The F test portion of Levene's test revealed that the two independent sample groups were of equal variance prior to the intervention. The t-test portion of the Levene's test identified that the two groups not only had an equality of variance but also the mean of the two groups was not significantly different. Because I failed to reject the null hypothesis, I could assume that my experimental and control groups were homogeneous at the time of the pre-test and was able to proceed with further analysis.

Independent t-Test on Posttests

The information in Table 2 reveals that the control and experimental posttest groups are not homogeneous (i.e., they are unequal in their variances, p < .05) and,

Table 1

Levene's Test for Independent Samples (Pretest)

Statement: "My family has discussed organ donation."

(1 = yes; 2 = no)

Variable	n	Mean	SD	SE of Mean
experimental	156	1.5449	.500	.040
control	142	1.5845	.495	.042

Mean Difference = .0396

Levene's Test for Equality of Variance: F = 1.785

P = .183

t-test for Equality of Means

Variances	t-value	df	1-Tail Sig
equal	-.69	296	.246

Table 2

Levene's Test for Independent Samples (Posttest)

Statement: "My family has discussed organ donation since taking the pretest." (1 = yes; 2 = no)

Variable	n	Mean	SD	SE of Mean
experimental	167	1.7066	.457	.035
control	145	1.8621	.346	.029

Mean Difference = -.1555

Levene's Test for Equality of Variance: F = 50.318

P = .000

t-test for Equality of Means

Variances	t-value	df	1-Tail Sig
unequal	-3.41	304.58	.000

thus, the null hypothesis was rejected. Not only are the two groups unequal in their variances, the *t*-test for the difference in their means is found to be significant ($p < .05$). It can be interpreted that, because the groups' variances had been found to be equal *prior* to the intervention and were significantly *not* equal after the intervention, then, *ceteris paribus*, the intervention made a difference in the means on the posttest.

In the experimental group, 49 participants (29.3%) reported having talked to their families *since* taking the pretest, while only 20 participants (13.8%) of the control group had. This represents a significant difference between the two groups and supports the hypothesis that a visual and interactive intervention such as the puppet program along with a brochure has a significantly greater likelihood of stimulating teenagers to initiate a discussion with their families than does handing out a brochure alone. Although 29.3% is not a majority, it represents an important proportion of the

total group, particularly in light of understanding that many adolescents turn away from their families at this time in their lives in their attempts to develop an identity and establish autonomy (Preto, 1989), and, therefore, any family discussion on any topic can be considered significant. It is interesting to note that, of the 49 family discussions reported on the posttest in the experimental group, 16 (32.6%) were "first-time" discussions. It also should be noted that receiving the brochure alone (control group) had some impact on family discussion of organ donation, with 20 (13.8%) of the control group reporting "yes" to that posttest question concerning family discussion. Of those 20 students, 6 were reporting first-time family discussions.

Paired t-Tests with Correlated Samples

To determine if the intervention (puppet program) had a significant influence on the participants' knowledge and attitudes toward organ donation, the pre- and posttests of the experimental group were analyzed

using paired *t*-tests for correlated samples (SPSS). Only paired tests (cases in which the same respondent answered both pre- and posttest questions) were used (*n* = 158 pairs). The cases where I could not match pre- and posttests were eliminated except for using any unmatched posttests in the analysis of the yes/no statement concerning the family discussion of organ donation since taking the pretest (*n* = 169 responses).

Not every attitude statement appeared to be modified by the intervention (see Table 3). The mean differences in 12 of the 20 pre- and posttest paired statements showed a significant change in the expected direction (Table 4). One statement revealed a very slight but significant change in the unexpected direction. A change in the expected direction means that, if the desired response to a statement is "strongly agree," then a shift from a higher value (strongly disagree = 5) on the pretest to a lower value (strongly agree = 1) on the posttest is considered the expected change. Likewise, if the desired response is "strongly disagree," then a shift

Table 3

Attitude and Knowledge Statements Not Significantly Modified By Intervention. Possible Range in Scores: 1 = strongly agree to 5 = strongly disagree.

Statement (including expected direction of change if intervention has desired effect on attitude)	Pretest mean	Posttest mean	1-tail sig.
1. If I had heart disease and the only way I could live would be to have a heart transplant, I would have it.(→1)	1.46	1.37	.055
2. If one of may parents had a life-threatening disease and the only chance of survival would be to have an organ transplant, I would want them to have it. (→1)	1.20	1.23	.224
4. Discussing organ donation and transplantation with my family makes me uncomfortable.	3.87	3.85	.448
6. If one of my family members were to die, I would know if he/she wanted to be an organ donor. (→1)	2.56	2.41	.054

(table continues)

Statement (including expected direction of change if intervention has desired effect on attitude)	Pretest mean	Posttest mean	1-tail sig.
7. My family's religious beliefs could prohibit me from donating my organs. (→5)	4.34	4.42	.156
16.It is important to talk about organ donation with my family <u>before</u> a situation arises where a decision needs to be made. (→1)	1.58	1.58	.500
18.If one of my family members died and his/her organs were donated, I would want to know who received them.	2.16	2.09	.219
19.Doctors should be allowed to presume that all people, at the time of death, are possible donors and be allowed to take their organs, if usable and needed, without next-of-kin permission. (→1)	3.80	3.87	.286

Table 4

Attitude and Knowledge Statements Significantly Modified By Intervention. Possible Range in Scores: 1 = strongly agree to 5 = strongly disagree.

Statement (including expecked direction of change if intervention has desired effect on attitude)	Pretest mean	Posttest mean	1-tail sig.
3. Organ transplantation is still mostly an experimental medical procedure. (→5)	3.14	3.69	.000
5. If doctors know that a person is a possible donor, they won't work as hard to save him/her. (→5)	3.88	4.28	.000
8. If I needed an organ transplant to live and the only available one was from someone of another race, I would be hesitant to have the surgery. (→5)	4.24	4.05	.017
9. Although a kidney transplant would lead to a better lifestyle, it is more economical for someone in kidney failure to be on dialysis (kidney machine). (→5)	3.72	4.08	.000

(table continues)

Statement (including expecked direction of change if intervention has desired effect on attitude)	Pretest mean	Posttest mean	1-tail sig.
10. Being brain dead is the same as being dead. (→1)	2.73	2.32	.000
11. When I sign a donor card, my name is place on a national computerized donor list. (→5)	2.19	3.15	.000
12.I worry that if I were in a coma and the hospital saw I had a donor card they would let me die to get my organs. (→5)	3.53	4.06	.000
13. Most people who receive an organ remain in fragile condition; although they are alive, they can't be expected to return to a full time job, etc. (→5)	3.57	4.13	.000
14.I would be willing to accept an organ from someone of a different sex. (→1)	1.88	1.71	.023
15. Doctors should be required to get the permission from the family of the donor before taking any organs.	2.08	1.78	.006

(table continues)

Statement (including expecked direction of change if intervention has desired effect on attitude)	Pretest mean	Posttest mean	1-tail sig.
17. The family of the deceased is expected to pay for the surgery to remove the organs. (→5)	3.91	4.36	.000
20. There cannot be an open casket funeral for someone who has donated organs due to the surgery involved in removing the organs. (→5)	3.81	4.51	.000

in value from low to high would be considered an expected change. A discussion of these results along with a summary of the overall worthiness of the instrument follows.

I was interested also in how receptive high school students would be to the puppet program format. The responses to one of the posttest puppet questions, "I saw Kids on the Block presentations when I was in elementary or middle school," indicated that a majority of the students (105 out of 157) were familiar with the Kids on the Block. Because of this association, I wondered if the puppets would be labeled as "childish." However, responding to the statement, "I think the puppets were an effective teaching method in my Driver's Education class," 130 said "yes", with only 27 saying "no." Additional support for using the puppets as an effective teaching method was seen in the responses to the statement, "I was insulted that puppets were used in my Driver's Education class." Twenty-four said they were,

but 124 were not. A final indicator that the puppets were well received was when the instructors from both schools telephoned me at the beginning of the 1996-97 school year to schedule the program for all of the driver's education and health classes for both terms.

5. DISCUSSION AND CONCLUSION

The pre- and posttests graphically demonstrated the effectiveness of the intervention in stimulating teenagers to discuss organ donation with their families. The response rates on the posttest statement regarding family discussion after the intervention showed a significant difference between the control and experimental groups. While the intervention did not result in a majority of the students discussing organ donation with their families, it did result in definitely more discussion compared to the control group.

I also attempted to gain insight into teenagers' knowledge of and attitude toward organ donation by examining the 20 attitude/knowledge statements. Although the results were favorable, (i.e., it appears Kids on the Block intervention did modify attitudes/knowledge on more than half of the 20 statements), a closer examination is required.

It is interesting to note that the statements showing significant modification in the expected direction were more specifically related to the arena of organ shortage. A brief discussion of some of these statements follows.

Statement 5: "If doctors know that a person is a possible donor, they won't work as hard to save him/her;" and Statement 12: "I worry that if I were in a coma and the hospital saw I had a donor card they would let me die to get my organs." Many people in the adult audiences at our performances throughout the years have disclosed a similar fear, which leads to the natural assumption that refusing to donate or not signing a donor card would improve one's chances of assistance and recovery. The puppet program addresses this issue directly, and the follow-up group processing led by the puppeteers immediately after the program supports and expands on what the puppets have said by explaining how EMTs (emergency medical technicians, or ambulance personnel)

and other medical personnel respond when they know that a person wants to be a donor. If EMTs are at the scene of an accident working on what they evaluate to be the case of a "hopeless" trauma victim and discover a donor card on that person, they will make all attempts to resuscitate that victim in order to keep at least the organs viable. The same is true once a person is hospitalized. If there is a chance that the patient will be an organ donor, extreme measures will be made to ensure that the organs will be in the best possible condition. In so doing, the overall care of the patient certainly is not jeopardized or threatened and, in fact, is possibly enhanced. This topic seems to be a source of great fear with many people, and, because of this, it is perhaps not surprising that education on the topic in this study did seem to make an important difference in the students' attitudes.

Statement 11: "When I sign a donor card my name is placed on a national computerized donor list." Another

apprehension of many Americans confronting the increasingly high-tech environment of organ transplantation is the fear of "Big Brother" watching via computer and then intervening. Many people do not want their names on computer lists. Again, many members of our adult audiences have expressed this fear as a reason for not signing a donor card: they fear being on a list. The donor card process is explained during the puppet program, and we emphasize that there is no master list. A donor is never on a "list" until after being declared brain dead and the family has signed the appropriate donor papers. He/she is then typed regarding blood, size, age, organs available, and so on. This information then is put into the computer to be matched with those people waiting for organs.

The main functions of the donor card are 2-fold: (a) In signing the card, because two witnesses are required (and if the person is under 18 years of age, at least one witness must be a parent or guardian), a discussion of

the topic would likely occur, leading to an understanding of how one feels; and (b) a signed donor card serves as an indicator to the next of kin if it is found with the victim at the time of death (this is particularly important if no prior discussion with the family has taken place). Both of these functions can make a profound difference on the family's decision-making process. As mentioned earlier, even when a donor card, which is a legal document, is found on someone, the medical professionals will still seek the permission of the living next of kin before removing any organs. The public often confuses the donor card with the computerized list of the people waiting for organs. A segment of the puppet program helps to clarify this confusion and explains the appropriateness of a minor (under age 18) signing a legal document (donor card).

Understanding the attention given to the treatment of potential donor patients and the function of the donor card gives greater impetus to the idea of communicating

and understanding the feelings of all family members. It is encouraging that the intervention in this study made such a significant difference in these two crucial areas. That there was a shift in the expected direction regarding more than half of the attitude statements is an affirmation of the validity of the intervention, particularly upon examination of each specific statement. In fact, it should be noted that all the statements showing a significant change in the expected direction in this sample were of a stronger, more critical nature than those showing no change, or else the statements showing no significant change scored so close to the maximum favorable response on the pretest that there was little room for significant change, or modification.

Statement 8, "If I needed an organ transplant to live and the only available one was from someone of another race, I would be hesitant to have the surgery." This was the only statement significantly modified in the unexpected direction. Although the program features an

African-American family, the topic of donors and recipients being of different races is not specifically addressed within the script. Often, during the question-and-answer time, this topic is discussed in length. However, I do not recall it surfacing during any of the performances for the driver's education classes. The scores from this statement on the pre- and posttests brought to my attention the importance of raising the race issue with each future performance. It should be noted, however, that the pretest score was close to the maximum expected score. Therefore, even though there was some movement away from the mean pretest score, which was statistically different, it was not deemed to be critical.

Other statements. Other statements of less critical nature showing no significant change are Statements 4 and 18. Statement 4, "Discussing organ donation and transplantation with my family makes me uncomfortable," is simply a statement that expresses a feeling toward an

action. It is the action that needs modification. However, the statement is directed toward the feeling of that action. Many people feel uncomfortable talking about organ donation with their families. I would not deny this, nor attempt to change it. I do think it is important to recognize during the program that many people share this discomfort, but I would not include the statement as it is worded if the study were to be repeated.

Another statement that I was not necessarily looking for modification on was Statement 18, "If one of my family members died and his/her organs were donated, I would want to know who received them." Although organ procurement organizations are becoming less rigid with their policies on disclosing recipient and donor family identities, the test statement was included purely for personal interest. Again, specifically agreeing or disagreeing with the statement was not an indicator of improved knowledge or communication of organ donation.

Four of the remaining six statements received desirable scores on the pretest, with little margin for modification (Table 3). Perhaps the wording of the statements was too suggestive of the favorable response or the statement already had an appropriate level of understanding. I believe this to be the case in statements 1,2, and 16.

Statement 7: "My family's religious beliefs could prohibit me from donating my organs" scored toward the high end (strongly disagree) of the range. However, I do not believe it was due to knowledge of the subject, but rather poor wording of the statement. Using the possessive pronoun "my" personalized it to the participants. The general population in the schools used in the study is mainstream Christian. All mainstream religions approve or support organ donation (Aiello, 1991). However, members of many audiences have shared with us their belief that some of the smaller recognized religious groups, such as Jehovah's Witnesses, do not

allow organ donation. The fact that this notion is false is not well known. Because the questionnaire statement was personalized by the word "my," I think the majority of participants read it to mean their own personal religious beliefs, rather than reflective of their knowledge of the role religion in general plays in organ donation.

Statement 19, "Doctors should be allowed to presume that all people, at the time of death, are possible donors and be allowed to take their organs, if usable and needed, without next-of-kin permission," was deemed to be wordy and confusing for a teenage audience since it showed no change and the response was very "middle of the road."

Invitations from the instructors to return the next school year, combined with the students' level of approval were strong indications of the worthiness and acceptance of the program. Because many of the students asked questions associated with transplant procedures and

recipients, we decided to include the second segment of the program, "Life Preservers," for future high school programs. "Life Preservers" is about a child who has received a heart transplant. This segment focuses on the issues of transplantation from a recipient's point of view.

I think it is important to reflect on the sample population for the study. Although random selection was desired in the initial plan for determination of the groups, limitations within the scheduling process prevented this. Knox County high schools had just converted to block scheduling, which increased the time allowance for each class period but allowed only four class periods a day. The problem this presented was that the driver's education classes were getting out of the classroom and onto the road driving in fewer days. This smaller window of opportunity was simultaneously shortened by a prolonged waiting period for the University's Institutional Review Board approval. By the

time the project was ready to go, I had to take whatever schools I could get. Letters and follow up phone calls were received by all driver's education departments in the Knox County system. While all teachers were responsive and interested in having the program, most were not able to participate due to conflicts in scheduling. It could be questioned that the teachers who were able to participate may have biased their classes responses., but checking for this is beyond the scope of this research. Although the sample schools were fairly representative of Knox County, there was a definite split between the control and experimental groups, with the experimental group having the greater percentage of African Americans, lower socioeconomic status, and lower TCAP scores. However, this could give even greater strength to the significant differences found between the control and experimental groups, given that minorities and lower socioeconomic groups are usually more likely to refuse to give consent for organ donation (Hall et al.,

1991; Morris et al., 1990). It would have been scientifically more sound if the two groups could have been divided on a more equitable basis regarding these important variables, but that was out of the scope of my control in this particular study.

By administering the posttest within 3 to 7 days following the intervention, I was limited to studying only the immediate impact the intervention had on the dependent variable, family discussion of organ donation. Often, families with teenagers have very limited time together. It is possible that discussion of any subject did not take place in that short amount of time. I was not able to measure the effect of the puppet program at a later time, perhaps after some other occurrence has caused the topic of organ donation to surface. The intervention may not have resulted in initiating the discussion of organ donation, but it could be a strong resource for supporting and implementing discussions and decisions pertaining to future organ donation dilemmas. A

positive aspect of the short time between the intervention and the posttest is that it reduced the possibility of intervening outside events taking place which could contaminate the results (such as the death of a friend or family member, or a newsworthy event such as Mickey Mantle's death).

A possibility for future research would be to survey the same students after they have received their drivers' licenses and observe if they have filled out the organ donor portion of their licenses.

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APPENDIXES

APPENDIX A

To: Driver Education Instructors, Knox County Schools
From: Becky Ferguson, graduate student, UTK
Date: February 14, 1996
re: Participation in research project for master's thesis

My name is Becky Ferguson and I am in graduate school in Child and Family Studies at The University of Tennessee, Knoxville. I have also worked in the Knox County school system with the program *Kids on the Block* for the last nine years. *Kids on the Block* is a program that takes sensitive subjects into the classroom and educates, communicates, and interacts with students through the use of puppetry. It is an international program and has been a part of the Knox County curriculum since the early eighties. However, it may be unknown to you because it has been exclusively in the elementary and middle schools.

In recent years we have experienced a growing popularity with adult audiences outside the school system. Part of my research is directed toward evaluating how the puppets are accepted in the high school environment. I am approaching Driver Education instructors because of the topic the puppets will be presenting - *organ donation and transplantation.*

For a number of years, the Tennessee Department of Safety has actively participated in the Organ Donor Label program for new and renewed driver licenses. I believe that the driver education classroom is an excellent environment for giving people good and adequate information for both making an informed decision concerning organ donation and sharing that decision with their families. The second objective of my research is to evaluate how effectively the *Kids on the Block* achieve this communication with families.

I will be happy to give you more background information concerning this particular *Kids on the Block* program and its main message (family communication) when I telephone you. My research has been approved by both the Knox County Office of Research and Evaluation (attached) and The University of Tennessee, Knoxville, Institutional Review Board. **The study will include a pretest, presentation (either control or experimental), and a posttest. The pretest and presentation will be done during one class period. The posttest will be conducted approximately one week later. Each test takes 10 - 15 minutes to complete and the puppet presentation takes 30 minutes.**

I realize your students are in the classroom for only the first part of the term, prior to getting out on the road. My goal is to get to all the participating schools before your students start driving. I look forward to speaking with you soon.

Thank you,

Becky Ferguson
2212 Woodson Drive
Knoxville, Tennessee

APPENDIX B

FORM B

IRB #_____

Date Received in ORC_____

THE UNIVERSITY OF TENNESSEE, KNOXVILLE

Application for Review of Research Involving Human Subjects

I. IDENTIFICATION OF PROJECT

Date_____

Principal Investigator:
Rebecca Venable Ferguson
2212 Woodson Drive
Knoxville, Tennessee 37920
423-577-3121

Advisor:
Julia A. Malia, Ph.D.
419 Jessie Harris Building
The University of Tennessee
Knoxville, Tennessee 37996-1900
423-974-6292

Title of Project:
Effect of puppet presentation to teenagers on attitudes and family communication regarding organ donation

Department:
Child and Family Studies

Starting date:
Upon IRB approval

Estimated completion date:
December, 1996

II. OBJECTIVE OF PROJECT:

The objective of this study is to evaluate if teenagers' attitudes and family communication regarding organ donation are affected by teenagers' viewing the *Kids on the Block* puppet program, "Gift of Life". A second objective is to evaluate how "acceptable" the *Kids on the Block* puppets are in a high school setting.

Unfortunately, one of the largest pools of potential donor candidates is made up of people between the ages of 16 and 25, due to this group's higher occurrence of driving fatalities. The relative well health of these people prior to the accidents makes them good potential donors. The Tennessee Department of Safety actively participates in the Organ Donor Label program for new and renewed driver licenses. The driver education classroom is an appropriate environment for such awareness-building.

Also, *Kids on the Block* puppet programs have been a part of the Knox County school curricula for over ten years. However, the programs have limited their presentations to the elementary and middle school audiences. This particular *Kids on the Block* program, "Gift of Life", has been used with many adult groups since its inception in April, 1991. The "Gift of Life", like all the *Kids on the Block* programs, focuses on the importance of good communication. The driver education classroom will provide a teenage audience to evaluate the effectiveness of this teaching tool with this age audience. An additional awareness of a teen's own mortality might also be realized.

III. DESCRIPTION OF SUBJECTS

The targeted population will be 15- to 16- year- old males and females. All driver education classes in the Knox County school system will be invited to participate. A private religious high school will also be a part of the study. A minimum of 200 students (100 comparison / 100 experimental) will be used. The time allotment for this study would allow a maximum of approximately 600 students. Because the number of students taking driver education varies greatly between high schools, I will randomly divide the schools willing to participate into two groups. I will then randomly select one group to be the experimental group, with the remaining being the comparison group. This should minimize the risk of contamination between the experimental and comparison groups.

IV. METHOD OR PROCEDURE

Letters will be sent to all driver education teachers in the Knox County school system informing them of the study (attachment 1). A phone call to each instructor will follow the letter, answering any questions and asking if they are willing to participate. At the time of the phone call, if the instructor is willing to participate, I will gather the information concerning the number of driver education classes and number of students in each class. I will randomly divide the schools willing to participate into two groups. I will randomly select one group to be the experimental group, with the remaining being the comparison group. After getting the minimum number of students committed for the study (200), I will telephone each instructor and arrange a date and time for the pretest and presentation (either

comparison or experimental). A statement of participation will be signed by each instructor on the day of the pretest. (attachment 2)

The pretest and classroom presentation (either control or experimental) require no more than one hour. Because the Knox County high school system now operates under block scheduling, with each class period lasting one hour and fifty minutes, time should not present a problem. I will introduce the project with a statement of purpose concerning organ donation and transplantation as detailed on the consent sheet (attachment 3). I will review all items on the consent sheet, making sure everyone understands it. This will be followed by the pretest (attachment 4). Upon completion of the pretest, the experimental group will view the *Kids on the Block* "Gift of Life" puppet presentation (attachment 5), while the control group will receive a presentation covering the Tennessee Department of Safety handout, "Give Life to Your License!" (attachment 6). The experimental group will also receive this handout.

If asked, I will tell them I will be returning at some point in time to give a posttest, but there will be no emphasis placed on this aspect of the study. Because one of the purposes of this study is to evaluate the effectiveness of the puppet presentation on initiating and stimulating family communication on the subject of organ donation, absolutely no mention will be made about the part of the posttest concerned with whether they have talked to their parents about organ donation since taking the pretest. I do not want to run the risk of contaminating my results in this way.

Approximately one week after the pretest, I will return to each class and administer the posttest, which is identical to the pretest, except for the question concerning talking to their families about organ donation (attachment 7). The experimental group will also have several questions concerning the use of the puppets as a teaching tool in the high school classroom added to the end of their posttest (attachment 7).

Data analysis will include evaluating the effect the puppet presentation had on changing teenagers' attitudes and initiating family communication regarding organ donation and transplantation when compared to the control group. Data will be stored in a secured location in the Department of Child and Family Studies on The University of Tennessee campus (Knoxville) and will remain there for three years following the completion of this study. Dr. Julia Malia and Rebecca Ferguson will be the only people having access to this data.

V. SPECIFIC RISKS AND PROTECTION MEASURES

The risk or harm anticipated in this proposed research is no greater than that ordinarily encountered in one's daily life. The research will be conducted in the students' normal classroom environment, using a teaching tool that is a part of the currently approved school curricula. The handout, "Giving Life to Your License", has been available to all driver education classes in the past.

Because of the need to match pre- and posttests, a coding system will be implemented. Adequate provisions have been made to maintain anonymity of all participants using this coding system. The following system will be used to code the

tests: *student's birth day - last four digits of driver permit audit number.* (The audit number on a driver permit is used only for auditing purposes with the Tennessee Department of Safety. All driver education students are required to have a permit before being admitted to the class. There are no records kept with the school that contain this number.) For example, if my birthday is April 8, and my driving permit number is 136037784, my code would be: 04-7784. Tests will be grouped by class. Any duplicate codes would be excluded from the study.

At the conclusion of the study the puppet presentation will be make available to the comparison group classes, if the instructors want it.

VI. BENEFITS VS. RISKS

Nationwide there is a dire shortage of organs available for transplantation. Education plays a vital role in altering this situation. But along with proper education on how transplantation works, there is the equally vital need to make one's personal wishes known to other family members. Studies show there is widespread public support for organ donation. *Required Request* laws mandating that hospitals approach families of eligible donors about organ donation have been passed in most states and are a requirement for federal Medicare reimbursement and hospital accreditation. Yet when it actually comes time to give consent, family members are reluctant to do so, unsure of how that loved one felt about donation. I believe that sharing and understanding one's feelings on this subject is of prime importance when searching for ways to increase the likelihood of a family giving consent. Talking about such a sensitive topic is most difficult at the time of a tragedy. If the subject

has never been broached, the likelihood of consent is low. The importance of discussing organ donation in a non-threatening, non-stressful environment should help to make these sensitive decisions easier when the situation arises. I believe the "Gift of Life" puppet program has a unique way of initiating and stimulating an awareness of this need. Although the "Gift of Life" program deals with a sensitive subject, i.e. death, I do not believe it poses a threat to the classroom. This particular program has been presented to elementary and middle school classes for over four years, with no history of concern expressed by parents or teachers.

VII. METHOD OF OBTAINING "INFORMED CONSENT" FROM SUBJECTS

The Consent Sheet (attachment 3) provides all necessary and legal documentation for informed consent, including a statement of purpose, minimal risks and benefits involved, statement and explanation of anonymity, statement of voluntary participation and withdrawal, and a contact person for questions. This consent sheet will be for each participant to keep.

A waiver to state the entire purpose of the study is requested. Stating the purpose of evaluating family communication at the pretest time of the study could bias the results of the study.

A waiver to obtain parental consent is also requested. Giving information to parents about this study could jeopardize one of the objectives of the study (effect program has on family communication). Because this study involves no more than minimal risk, is with older children (15-to-16- year-olds), is for purposes of

evaluating an approved school curriculum tool (*Kids on the Block)*, and has appropriate mechanisms for protecting the anonymity of the participants, I believe this is a reasonable request.

The coding system allows me to match pre- and posttest while keeping the identity of the participants anonymous. Since they are anonymous, the pre- and posttest will be considered similar to a "drop-box". A consent sheet will provide all of the informed consent information and the indication that the return of the pre- or posttest will constitute the subject's informed consent to participate.

VIII. QUALIFICATIONS OF THE INVESTIGATOR

I have worked with the Greater Knoxville *Kids on the Block* for eight years, as both a puppeteer and puppeteer trainer. This has required extensive training in both the field of puppetry skills and background information on all presented topics. These topics include, but are not limited to, sexual and physical child abuse, fire safety instruction, multiple physical and mental disabilities, teen pregnancy, divorce, and organ donation and transplantation. I was also a member of the local research and development team, which worked with the national *Kids on the Block, Inc.,* creating the "Gift of Life" program. Along with many local performances, I have also presented this particular program to various medical and medical support groups throughout the nation. Because of my awareness of both the popularity of this program with adult audiences and the need for better educational and communication tools regarding organ donation and transplantation, I feel competent initiating and investigating this research.

IX. RESPONSIBILITY OF PROJECT DIRECTOR

By the Compliance with the policies established by The University of Tennessee, Knoxville, Committee on Research Participation, the principal investigator subscribes to the principles stated in "The Belmont Report" and standards of professional ethics in all research, development, and related activities involving human subjects under the auspices of The University of Tennessee, Knoxville.

Principal Investigator Rebecca Venable Ferguson
Name

Signature Date

Advisor Julia A Malia, Ph.D.
Name

Signature Date

X. DEPARTMENTAL REVIEW

Department Head Connie Steele, Ph.D.
Name

Signature Date

The application described above has been reviewed by the departmental committee and has been approved.

Chair,
Departmental
Review
Committee: Jo Lynn Cunningham, Ph.D.
Name

Signature Date

Approved: Steve Pulik
Coordinator of Compliance
Research Administration

Signature Date

Knox County Schools

Permission to Conduct Research

January 18, 1996

TO: Principals of all high schools

Subject of Research: Attitudes about organ donation
Name of Researcher: Rebecca V. Ferguson
Position: Graduate student, Child and Family Studies, UTK
Supervisor/Associate (if applicable):

Ms. Rebecca V. Ferguson has received permission to contact you concerning her research study entitled, "Effect of Puppet Presentation to Teenagers on Attitudes and Family Communication Regarding Organ Donation." Although this study has been approved at the central office level, it is our policy to allow the building-level administrator the right to accept or reject a given research project for his/her school or administrative unit. If you have questions or concerns about this project, telephone me at 594-1740. Thank you for your careful consideration of this study.

Samuel E. Bratton, Jr.

Samuel E. Bratton, Jr.
Coordinator of Research and Evaluation

Project No. 623

xc: Dr. J. W. Phifer, Coordinator of High Schools
Ms. Rebecca V. Ferguson

THE UNIVERSITY OF TENNESSEE
KNOXVILLE

Office of Research
[illegible]
Knoxville, Tennessee [illegible]
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URL http://www.[illegible]

03/21/96

IRB # : 5008 B

Title : Effect of Puppet Presentation to Teenagers on Attitudes and Family Communication Regarding Organ Donation

Ferguson, Rebecca
Child & Family Studies
2212 Woodson Drive
Knoxville, TN 37920

Malia, Dr. Julia
Child & Family Studies
419 Jessie Harris Bldg.
Campus

Your project listed above was reviewed. It qualified for expedited review and has been approved.

This approval is for a period ending one year from the date of this letter. Please make timely submission of renewal or prompt notification of project termination (see item #3 below).

Responsibilities of the investigator during the conduct of this project include the following:

1. To obtain prior approval from the Committee before instituting any changes in the project.
2. To retain signed consent forms from subjects for at least three years following completion of the project.
3. To submit a Form D to report changes in the project or to report termination at 12-month or less intervals.

The Committee wishes you every success in your research endeavor. This office will send you a renewal notice on the anniversary of your approval date.

Sincerely,

Steven B. Pulik
Coordinator of Compliances

cc: Dr. Connie Steele

APPENDIX C

Pretest
Issues in Organ Donation and Transplantation

Code: __ __ - __ __ __ __ (birth day - last four digits of driving permit number)

I am interested in your attitude toward and knowledge of organ donation and transplantation. Please answer the following statements as honestly as you can. *Circle* the number which most closely matches your feeling, belief, or attitude toward the statement, with the numbers representing the following:

1= strongly agree
2= agree
3= neither agree nor disagree
4 disagree
5= strongly disagree

	strongly agree				strongly disagree
	1	2	3	4	5
1. If I had heart disease and the *only* way I could live would be to have a heart transplant, I would have it	1	2	3	4	5
2. If one of my parents had a life-threatening disease and the only chance of survival would be to have an organ transplant, I would want them to have it	1	2	3	4	5
3. Organ transplantation is still mostly an experimental medical procedure	1	2	3	4	5
4. Discussing organ donation and transplantation with my family makes me uncomfortable	1	2	3	4	5
5. If doctors know that a person is a possible donor, they won't work as hard to save him/her	1	2	3	4	5
6. If one of my family members were to die, I would know if he/she wanted to be an organ donor	1	2	3	4	5
7. My family's religious beliefs could prohibit me from donating my organs	1	2	3	4	5
8. If I needed an organ transplant to live and the only available one was from someone of another race, I would be hesitant to have the surgery	1	2	3	4	5

	strongly agree				strongly disagree
9. Although a kidney transplant would lead to a better life style, it is more economical for someone in kidney failure to be on dialysis (kidney machine)	1	2	3	4	5
10. Being *brain dead* is the same as being *dead*	1	2	3	4	5
11. When I sign a donor card, my name is placed on a national computerized donor list	1	2	3	4	5
12. I worry that if I were in a coma and the hospital saw I had a donor card they would let me die to get my organs	1	2	3	4	5
13. Most people who receive an organ remain in fragile condition, although they are alive, they can't be expected to return to a full time job, etc	1	2	3	4	5
14. I would be willing to accept an organ from someone of a different sex	1	2	3	4	5
15. Doctors should be required to get the permission from the family of the donor before taking any organs	1	2	3	4	5
16. It is important to talk about organ donation with my family *before* a situation arises where a decision needs to be made	1	2	3	4	5
17. The family of the deceased is expected to pay for the surgery to remove the organs	1	2	3	4	5
18. If one of my family members died and his/her organs were donated, I would want to know who received them	1	2	3	4	5
19. Doctors should be allowed to presume that all people, at the time of death, are possible donors and be allowed to take their organs, if usable and needed, without next-of-kin permission	1	2	3	4	5
20. There cannot be an "open casket" funeral for someone who has donated organs due to the surgery involved in removing the organs	1	2	3	4	5

Please circle the appropriate answer to each of the following questions:

I carry a signed organ donor card with me.	yes	no
I know someone who has received an organ.	yes	no
I know someone who has donated an organ.	yes	no
My family has discussed organ donation.	yes	no
My family understands how each member feels concerning organ donation.	yes	no

(Last page of Posttest - Experimental group)
Please circle the appropriate answer to each of the following questions:

I carry a signed organ donor card with me.	yes	no
I know someone who has received an organ.	yes	no
I know someone who has donated an organ.	yes	no
My family has discussed organ donation *since* taking the pretest.	yes	no
My family understands how each member feels concerning organ donation.	yes	no
I had never heard of the *Kids on the Block* until seeing the performance in Driver Education class.	yes	no
The *Kids on the Block* "Gift of Life" presentation was the first *Kids on the Block* presentation I have ever seen.	yes	no
I saw *Kids on the Block* presentations when I was in elementary or middle school. (not necessarily the same topic you saw in Driver Eduation).	yes	no
I think the puppets were an effective teaching method in my Driver Education class.	yes	no
I was insulted that puppets were used in my Driver Education class.	yes	no

APPENDIX D

ABOUT THE PROGRAM

THE GIFT OF LIFE is The Kids on the Block puppet program on organ donation and transplant. The puppet program is designed to be performed for both children and adults and can be performed in schools with classroom students, in hospitals with children who are waiting for or who have just received an organ transplant, with adults in the same situation, and/or for community members as a public awareness activity.

The program contains three puppet characters and three scripts. The characters are:

ALEX LANDRY - an eleven year old boy who has received a heart transplant

MELODY JAMES - an eleven year old girl, friend of Alex's whose older brother died and donated his organs

MICHAEL RILEY - an eleven year old boy, classmate of Melody's and new friend to Alex who is curious about both donation and transplant

These characters have been created so that a number of important aspects about donation and transplant can be explained. Alex demonstrates the how and why of organ transplant and discusses his own experience as a recipient of a new heart. Melody discusses organ donation from a personal perspective because it was her older brother Darryll who died suddenly and who had earlier told his family that he wanted to be an organ donor. Mike represents the point of view of the general public which often subscribes to myths and misconceptions about the nature of organ transplant and the decision to donate organs as well.

The scripts included in this program allow you to perform effectively for audiences which are adult only, audiences which are mixed -- that is, with both children and adults present -- audiences of classroom children, and support/hospital groups where your audience is comprised of organ donation recipients and/or families whose members have become donors.

Finally, each script contains a public awareness message which can be used for any group in your community to introduce and discuss the important, life giving issue of organ donation.

APPEMDIX E

WHY GIVE?

Medical science makes it possible to save lives and improve the quality of life with the transplantation of donated organs and tissues. Many Tennesseans today are waiting for these organs and tissues, but there is a shortage. Organ and tissue donation is something everyone can do to help fellow human beings. Studies show that it is also of great benefit to families in grief to know that their loved one has made so generous a gift. It is important to make the decision now and discuss it with your family. When the time comes, this makes the decision much easier for family members. Tennessee law requires that families of potential organ and tissue donors be offered the opportunity to donate at the time of their loved ones death.

Organ and tissue donation is done at no cost to the donor's family, but it is one of the most worthy gifts a person can give. By deciding to be a donor now and signing your donor card, you will be expressing your wish to give life to others in need.

This brochure is sponsored by the Tennessee Department of Safety in cooperation with Tennessee Donor Services.

Always keep this card in back of your license

By signing the front of this card as donor, I certify that I am eighteen (18) years of age or over, and being of sound mind, I agree to donate the organ(s)/tissue(s) specified at the time of death.

Important: This card must be signed in the presence of two witnesses, who must sign in the presence of the donor.

This is a legal document in compliance with Tennessee code annotated 55-50-352 and 68-30-105.

For more information regarding organ and tissue donation, please contact the following agencies in your area:

East Tennessee

Life Resources	(615) 929-1638
East Tennessee Eye Bank	(615) 544-9625

Knoxville Area

Tennessee Donor Services	(615) 523-4432
East Tennessee Eye Bank	(615) 544-9625
U.T. Tissue Bank Services	(615) 544-9706

Nashville Area

Tennessee Donor Services	(615) 327-2247
Tennessee Donor Services Tissue Bank	(615) 327-2247
Lions Eye Bank	(615) 321-3937

Chattanooga Area

Tennessee Donor Services	(615) 267-1010
Lions Eye Bank	(615) 778-4000

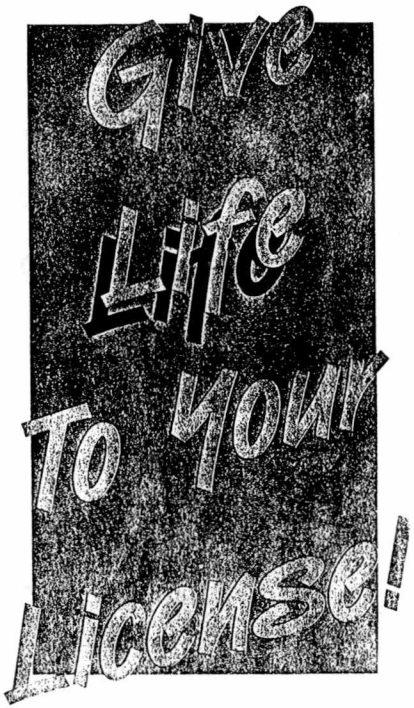
Jackson Area

Tennessee Donor Services	(901) 668-6021

Memphis Area

Midsouth Transplant Foundation	(901) 528-5923
Midsouth Eye Bank	(901) 726-8264
Baptist Memorial Bone Bank	(901) 522-5930
Regional Medical Center Skin Bank	(901) 575-8313

Tennessee Department of Safety; Authorization No. 349086, 500,000 copies. This public document was promulgated at a cost of $.045 each. July 1989.



Sign an Organ Donor Card

THANK YOU FOR CONSIDERING ORGAN DONATION

Organ and tissue donation can bring the gift of life to someone in serious medical need. In this brochure you will learn how to become a donor and why your decision is so important.

There is a shortage of organs and tissues for transplantation. Today, hundreds of Tennesseans fill local waiting lists for these much needed organs and tissues.

Organ and tissue donation is one of the most important ways you can help. After you have read this brochure carefully, please sign the attached donor card and carry it with your Tennessee Driver License at all times. Discuss your decision with your family. Let them know you want to be a donor and learn their feelings too.

WHO CAN BE A DONOR?

Everyone can be considered an organ and tissue donor regardless of age or previous illness. The decision as to whether a donor is accepted will be made at the time of the donor's death.

WHAT ORGANS AND TISSUES CAN BE DONATED?

Organs	Tissues
Heart	Eyes
Lungs	Heart Valves
Liver	Saphenous Veins
Kidneys	Select Bones
Pancreas	Tendons
	Skin

HOW CAN I BECOME AN ORGAN AND TISSUE DONOR?

1. Have a family discussion and inform them of your wishes.
2. Complete the attached donor card.
3. Apply an Organ Donor label (available at any Tennessee Driver License Center) to the front of your license.

CAN I SPECIFY THE ORGANS AND TISSUES I DONATE?

Yes. Simply write the organs or tissues you wish to donate in the space provided on the card. You may change your mind at any time by destroying the card and removing the Organ Donor label from your license. Also, remember to inform your next-of-kin of your decision.

IS THERE ANY COST INVOLVED?

No. There is absolutely no cost to your family should you decide to become a donor. The local organ donor agency covers 100% of any costs involved in donation after consent has been obtained.

CAN MY FAMILY REVERSE MY DECISION?

Medical personnel will not remove organs unless the family agrees. The presence of a signed donor card indicating your wishes makes discussions between your doctor and your family less difficult. It helps reduce the responsibility of the decision from your family.

Donations are also accepted from people who do not or cannot sign a donor card, but whose families give permission for the donation to take place.

ARE THERE ANY RELIGIOUS CONFLICTS?

No. Organ and Tissue donation gives a gift of life to others. As such, it is consistent with the beliefs and attitudes of most major religions and ethical traditions.

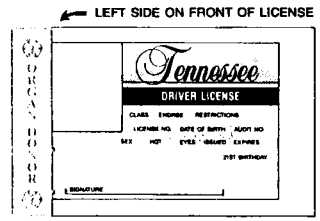
WILL DONATION INTERFERE WITH FUNERAL ARRANGEMENTS?

No. Donation does not interfere with funeral arrangements. An open casket funeral is possible with donation. Regular funeral costs, memorial services, or burial arrangements remain the responsibility of your family.

WHAT SHOULD I DO NOW?

After you decide to be a donor, please follow these important directions:

1. In order to be on record with the Tennessee Department of Safety as a donor, you must provide this information when applying for or renewing your driver license.
2. Obtain an Organ Donor label available at any Tennessee Driver License Center.
3. Apply the label as illustrated below.



4. Complete the attached Tennessee Organ Donor Card.
5. Follow the donor/witness signature instructions listed on the back of the donor card.
6. Have a family discussion and inform them of your decision.

DETACH HERE

Tennessee ORGAN DONOR CARD

Donor Information

NAME (Signature)		DATE OF BIRTH
ADDRESS		SOCIAL SECURITY NO.
DRIVER LICENSE NO.	ORGAN(S)/TISSUE(S) DONATED	BLOOD TYPE
WITNESS NO. 1 (Signature)		RELATIONSHIP
WITNESS NO. 2 (Signature)		RELATIONSHIP

APPENDIX F

Agreement of Participation/Cooperation

As an instructor of driver education in the Knox County school system, I agree to participate in Becky Ferguson's research on the effect of *The Kids on the Block* puppet presentation to teenagers in driver education classes on attitudes and family communication regarding organ and transplantation. I understand that this project has been approved by the Knox County Schools Coordinator of Research and Evaluation, Sam Bratton, and The University of Tennessee Institutional Review Board

Ms. Ferguson and I have discussed the project and I understand that the students in my class will be given a questionnaire concerning organ donation and transplantation followed by either a pamphlet or puppet presentation. Ms. Ferguson will return to my class approximately one week later with a followup questionnaire. Her first visit will take approximately twenty minutes (questionnaire and pamphlet presentation) *or* one hour (questionnaire and puppet presentation). The second visit will take approximately fifteen minutes.

I am also aware that if my class is part of the control group (pamphlet presentation) I can request that the puppet presentation be presented to my class after the research is completed.

_____ _____

Instructor signature date

_____ _____

Principal researcher date

APPENDIX G

Consent Statement:

Issues in Organ Donation and Transplantation

The purpose of this questionnaire is to determine what attitudes teenagers have toward organ donation and transplantation prior to receiving educational information on the subjects. The risk or harm anticipated in this proposed research is no greater than that ordinarily encountered in one's daily life.

Your participation in this study involves answering a questionnaire before and after receiving information on organ donation and transplantation. Your participation is voluntary, and you may decline or withdraw from participation at any time without penalty or prejudice of any kind. Your return of the tests will constitute your consent to participate in this study. It should take only 10 - 15 minutes for you to complete each test. I will return within one week to administer the second test.

In order to keep your name from appearing on each of the two tests, I ask that each of you write out a code on your questionnaires, using the following method:

birth day - last four digits of your permit number

For example, if your birthday is April 8, and your permit number is 36037784, your code would be: 08-7784.

If you have any questions about the research, either now or later, please contact Becky Ferguson, Child and Family Studies Department, 115 Jesse Harris Building, The University of Tennessee, Knoxville, Tennessee 37996-1900, or call 974-5316.

VITA

Rebecca Venable Ferguson was born in Knoxville, Tennessee, on October 27,1951. She attended schools in the Knxoville City School System, where she graduated from West High School in June, 1969. She entered The University of Tennessee, Knoxville, That same month and graduated with a Bachelor of Science in Home Economics, with a major in Food Science, in June, 1973. The following spring she received vocational certification in Home Economics Education from The University of Tennessee. In August of 1993, she reentered The University of Tennessee and in December, 1996, received a Master of Science degree in Child and Family Studies.