



Age-based Considerations in Educating Children About Organ Transplantation

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Abstract

This study sought undergraduate nursing student views on the best method for educating children of different ages about organ transplantation when they are candidates for the procedure. This was a cross-sectional survey of volunteers who completed a questionnaire. For children under age 6, the students indicated most often that the best method to teach them was "Parents talk to the child." For children aged 6-11, two answers were commonly provided: "One-on-one teaching by a transplant nurse" and "Group classes of children own age by transplantation team." For children aged 12-17, the most common answer was "One-on-one teaching by transplant nurse." As such, the child's age greatly influenced their answers, an understandable and expected finding. However, it is important to consider that chronically-ill children who have had frequent healthcare experiences are likely to have different learning needs and abilities as compared to well children their own age, and so research is needed now to determine if conventional views about the way to teach them (and particularly those under the age of 6) are correct.

Keywords: education; children; organ transplantation; nursing.

Introduction

Organ transplantation has become a highly effective therapy for many of the children who suffer from irreversible and potentially fatal illnesses (Shellmer et al., 2014). For two decades, this surgical treatment has had high rates of immediate survival, while also promising and delivering many additional years of life (Kim & Marks, 2014). Although people often think organ transplantation provides a cure for an illness, instead it offers each recipient the possibility of living with a more sustainable and manageable chronic illness (Anton & Piccinini, 2011).

Both the immediate surgery and the post-surgery requirements for maintaining the health of the transplanted organ pose many physical, emotional, and psychosocial challenges for children (Gritti et al., 2001; LaRosa et al., 2011). Education is therefore critical, so they understand the option of accepting or declining the transplantation surgery and also so they can understand how their future health and life will be impacted by the transplanted organ.

Study Purpose

Nurses are extensively involved in patient education, including the education of children and their families about organ transplantation (Stegenga et al., 2019). However, few studies have been done to inform the nursing education of children, at varying ages, who require transplantation. Moreover, few studies have been done to gain the viewpoints or understandings of student nurses about how nurses should plan or provide patient education for this population group. To that end, a cross-sectional exploratory-descriptive study was done to identify what undergraduate nursing students consider are the best methods to educate pediatric patients of different ages about organ transplantation.

Student nurses were considered an appropriate subject audience, as they are typically younger and are therefore likely to have unique perspectives as compared to older or career experienced nurses. The findings of this study are intended to be of use to nurses and other health educators, and also children and their parents facing organ transplantation.

Education Considerations for Children

Children and other young people who live with potentially life-limiting illnesses, and the treatments that go with these, typically have feelings of lifestyle restrictions (Gritti et al., 2001; LaRosa et al., 2011). They often think they are different from other children their own age (Gritti et al., 2001; LaRosa et al., 2011). Moreover, they tend to have considerable anxiety over their current and future health (Gritti et al., 2001; LaRosa et al., 2011). This stressful situation can influence their psychological development, and thus their ability to live fully even when experiencing maximally beneficial treatment outcomes (Kärrfelt et al., 2003). Chronic illnesses of all types have impacts that are increasingly being recognized as having serious immediate and long-term consequences for children. These consequences necessitate an assessment of each child's psychological and social functioning before and after any transplant procedure (Shellmer et al., 2014).

Although receiving an organ and gaining benefit from it may be presented to children

as simple and straightforward, young recipients need to understand the implications of this major surgery and the lifelong limitations that a transplanted organ will impose on them. Among these is the continuing need for immunosuppression drugs, and their significant side effects such as an increased risk of infections and developmental delays (Anton & Piccinini, 2011; LaRosa et al., 2011). Living with a transplanted organ would be challenging for children of all ages, but adolescents have been found to be more significantly upset by these challenges (Anton & Piccinini, 2011; Bell et al., 2008).

Manworren and Woodring (1998) determined that children can see the surgical procedure and associated hospitalization as a form of punishment. This negative perspective supports the requirement that the transplantation process be discussed with the child to prevent it becoming a traumatic experience for them (Anton & Piccinini, 2010; Kärrfelt et al., 2003; Shellmer et al., 2014). Moreover, transplantation does not just affect the recipient, but all their family members and many others, including their healthcare providers (Anton & Piccinini, 2010). Among these are nurses, particularly pediatric nurses who tend to see the same young patients over and over again as illness episodes occur and as multiple workups for potentially available organs are also possible. As such, caring and trusting relationships are often formed between the nurse and the young patient and their family.

For the transplant to go ahead, the young recipient and their parents must learn a wide range of information, often within a short time span (Shellmer et al., 2014; Thys et al., 2014). However, children typically end up being much less involved than their parents in decisions about their illness and any or all treatments for it (Shellmer et al., 2014; Thys et al., 2014). Traditionally, parents have made all of the healthcare decisions for their children, including those related to transplantation. Some parents do this autonomous decision-making as they are extremely uncomfortable talking with their child about the deceased donor and even the need for the organ transplantation, and particularly when the alternative is progressive illness and eventual death.

However, education provides recipients with essential knowledge and skills, and so it is now widely viewed as a major support for life and life changes (Cupples et al., 2017; Kelo et al., 2013). In the case of pediatric organ transplantation, education has the potential to improve the child's essential understandings of their illness and all possible treatments. Education also encourages and enables the child to express their emotions, while establishing a link between them and the health team, and it enhances their ability to gain and use coping strategies (Manworren & Woodring, 1998). Education is therefore essential for the child who is a candidate for a transplant procedure, as it enhances the long-term viability of the organ and its vital role in sustaining life.

Transplant nurses have a critical role in organ transplantation, as they need to plan and deliver high-level care in both the pre- and post-transplant periods (Cupples et al., 2017; Mendes et al., 2012). Prior to the transplantation surgery, nurses will have done a great deal already to help chronically-ill patients, such as developing and implementing interventions to maintain or improve emotional, psychological, and social health; facilitating and promoting behavioral changes and treatment adherence; supporting patients and their families; and devising teaching and learning strategies to develop the knowledge and skills that enhance self-care abilities (Mendes et al., 2012). It is therefore of concern that undergraduate nursing

Benedetti, C. F. S., & Wilson, D. M.

Age-based Considerations in Educating Children About Organ Transplantation

students are rarely taught or receive planned educational material focused on organ donation and transplantation (Cerrato et al., 2017; Hoy, 2017). Given this deficit, nursing students may not learn how critical patient education is for the health and wellbeing of children who suffer from renal failure and other common conditions for which organ transplantation is indicated. As a first step toward addressing this gap, this study was intended to seek the views of undergraduate nursing students about the best methods for educating children of different ages about organ transplantation.

Methods

This study involved a survey that was provided directly to undergraduate nursing students to complete voluntarily by a student nurse researcher after the teaching professors had left the room. The data collection tool was developed after a careful assessment of survey methods, survey questions, and appropriate childhood age ranges that are relevant for patient education considerations. This tool was designed with a minimal number of questions to increase the return rate. It has two socio-demographic questions, three research questions about the best education method for child of different ages about organ transplantation, and three open answer questions that asked the participants to explain their answers to the three research questions. After research ethics approval was obtained for this study (University of Alberta Health Research Ethics Committee, ID: Pro00077448), the tool and a letter of information about the study were distributed to all five groups of students who were taking the research course that every undergraduate nursing student at a university in Canada must take.

After the students in each of the five classes were informed verbally about the study, and were provided the information letter and had an opportunity to ask questions, all were asked to complete the survey in class. Data collection occurred beginning October 1, 2017 through January 22, 2018. Instead of a signed consent form from each participant, which would then identify them, the university's research ethics committee had determined that all students who completed and returned the questionnaire had provided implied consent. Signed consent forms were therefore not distributed nor collected.

As indicated, the tool was designed to be short to encourage participation, with only 10-15 minutes intended for completion. Moreover, the questions were kept short and simple to ensure that the intent of the survey and all questions were clearly understandable to all. A pre-test was used to validate it. Once the completed surveys were collected, the quantitative and qualitative data in them were entered into a computer spreadsheet and this spreadsheet data was checked by two researchers for accuracy.

The quantitative data were then analyzed using the SPSS (version 21) computer software program (IBM SPSS Statistics, IBM Corporation, Armonk, NY, United States). Descriptive statistics were first used to describe the sample. Following this, bivariate tests were used to answer the questions. More specifically, chi-square (X^2) tests were used to compare categorical variables. Continuous variables were analyzed using ANOVA or t tests, as well as correlational tests. Following this, content analysis was conducted on the qualitative data that was provided by most, but not all, students.

Findings

Participants

The survey was distributed to 257 undergraduate nursing students, with 64.2% (n=165) completing and returning it. The participants in each class numbered from 24 to 40. The 165 participants ranged in age from 17 to 44 years old. Their mean age was 22.5 years, with a median age of 21.6 and a mode of 19 (46 or 27.9% of the total were 19 years of age). Moreover, 85.5% (n=141) of the participants were female and 14.5% (n=24) were male.

Quantitative Findings

The findings for each of the three research questions are summarized in Table 1. A discussion of these findings for each research question follows. Of note, all 165 students responded to the three questions.

Table 1 – Choice of Methods to Teach Children by Child Age Group

Answer Options (choose one)	Child <6 years	Child Aged 6-11	Child Aged 12-17
<i>Parents talk to child</i>	N= 70 (42.4%)	N= 22 (13.3%)	N=3 (1.8%)
<i>A booklet designed to teach children</i>	N=20 (12.1%)	N=17 (10.3%)	N=12 (7.3%)
<i>One-on-one teaching by transplant nurse</i>	N= 31 (18.8%)	N= 44 (26.7%)	N=54 (32.7%)
<i>One-on-one teaching by transplant doctor</i>	N=6 (3.6%)	N=9 (5.5%)	N=38 (23.0%)
<i>Group classes of children own age taught by transplantation team</i>	N=9 (5.5%)	N=44 (26.7%)	N=30 (18.2%)
<i>Not sure</i>	N=13 (7.9%)	N=14 (8.5%)	N=6 (3.6%)
<i>More than one</i>	N= 16 (9.7%)	N=15 (9.1%)	N=22(13.3%)

Question 1: Best educational method to teach a child under the age of 6 years.

Among the 165 students responding to this question, 42.4% (n=70) indicated that the best method is for the “Parents to talk to the child.” An additional 18.8% (n=31) considered “One-on-one teaching by the transplant nurse” was the best method, while 12.1% (n=20) chose “A booklet designed to teach young children” and 9.7% (n=16) chose more than one alternative.

Question 2: Best education method to teach a child aged 6 to 11 years. In response to this question, two equally common answers were provided by the 165 students: “One-on-one teaching by a transplant nurse” (26.7% or n=44) and “Group classes of children own age by transplantation team” (26.7% or n=44). Following this, 22 (13.3%) chose “Parents talk to child,” 17 (10.3%) chose “A booklet designed to teach children aged 6-11,” and 15 or 9.1% marked more than one alternative.

Question 3: Best education method to teach a child aged 12 to 17 years. The answers to this question provided by the 165 students were more varied, as the most common answer was “One-on-one teaching by transplant nurse” (32.7%, n=54). Following this, 38

Benedetti, C. F. S., & Wilson, D. M.

Age-based Considerations in Educating Children About Organ Transplantation

(23%) chose “One-on-one teaching by a transplant doctor,” 18.2% (n=30) chose the option “Group classes of children own age by transplantation team,” and 22 (13.3%) marked more than one alternative.

Statistical Comparisons

Only twenty five (15.2%) students gave the same answer to all three research questions, while most (n=140 or 84.8%) chose different answers, with this indicating that they took into consideration the varying ages of the children. This finding indicates most students thought the age of the child to be a relevant or key factor in educational learning and thus teaching methods. Among the students, relatively few response differences were noted in relation to student gender. Overall, 85.8% (n=121) of the female participants chose different options for the three questions, while 14.2% (n=20) the same answer for all three questions. Similarly, 79.2% (n=19) of the male participants chose different options for the three questions, while 20.8% (n=5) chose the same option for all three questions. A chi square test did not find this gender difference to be significant ($X^2=.705$, $df=1$, $p=.401$).

Moreover, a t-test did not reveal a difference in the mean ages of those who kept the same answers and those who changed them ($t=.148$, $df=162$, $p=.882$). The students who did not change their answers had a mean age of 22.7 years as compared to the 140 students who did and had a mean age of 22.5.

A chi square test was then done to determine if there was a class effect, with students in each class possibly influenced the other students in their class. No class effect was found in relation to those who provided the same answer to the three questions or changed them ($X^2=8.556$, $df=4$, $p=.073$).

Other potential student differences in relation to how they answered the three questions were examined, and some significant differences were identified. For the first question, which asked the students to choose one of six options, a significant difference in answers in association with the age of the students was found ($F=2.219$, $p=.044$). The youngest students most often chose the option of “Parents talking to their child,” while the oldest students alternatively chose “not sure,” “one-on-one teaching by transplant doctor,” or “group classes.” Another significant finding for Question 1 was noted when student age was correlated with their either choosing the option “Parents talk to the child” or any of the remaining options. In total, 71 students (43.0%) chose “Parents talk to the child,” while the remaining 94 or 57.0% chose another option. This analysis used Kendall's tau and Spearman's rho correlation tests, with significant values for both (Kendall's tau $r=.894$, $p=-.009$ and Spearman's $r=.895$, $p=-.010$). As such, younger nursing students were significantly more likely to choose the option of parents as a source of instruction for children under 6 years of age. In contrast, for question 2, which sought to determine the best of six ways to teach children aged 6-11, no difference in the student responses in relation to student age was found ($F=.354$, $p=.907$). Similarly, for question 3, which sought to determine the best of six ways to teach children aged 12-17, no difference in student responses in relation to student age was found ($F=.849$, $p=.534$).

Potential student gender-based differences in their responses to the three questions

were also examined. For question 1, the gender of students was found to be significant (Pearson $\chi^2 = 13.144$, $df=6$, $p=.041$). Among the 70 students (42.4%) who chose the alternative “Parents talk to child,” 50% of all male students and 41.1% of all female students chose this option. In contrast, for question 2, the gender of the students was not found to be a significant factor (Pearson $\chi^2 = 4.50$, $df=6$, $p=.609$). Similarly, for question 3, the gender of the students was not a significant factor (Pearson $\chi^2 = 9.567$, $df=6$, $p=.144$).

Finally, Hawthorne or peer effect differences in the answers provided by each group of students for the three research questions were examined through testing for differences by the class of the students. No class influence was found using chi square analysis for Question 1 ($X^2=29.789$, $df=4$, $p=.192$). Similarly, no class influence was found using chi square analysis for Question 2 ($X^2=24.107$, $df=4$, $p=.456$) and for Question 3 ($X^2=25.733$, $df=4$, $p=.367$).

Qualitative Findings

Qualitative data were obtained from nearly all students, with these being written justifications for how they answered the three research questions. These data were assessed as a whole and determined to fall into eight distinct categories: (a) Parental relationship with the child, (b) Nurse relationship with the child, (c) Doctor’s practical medical knowledge, (d) Nurse’s practical healthcare knowledge, (e) Booklets as the best learning method, (f) Multi-professional approach, (g) Support from other children, and (h) Parents and healthcare professionals. The following discusses these categorical findings in relation to the three age-based sets of children.

Best educational method to teach a child under the age of 6 years. For the youngest children, most of the answers from students focused on the child’s developmental stage and thus their capacity to understand complex educational content. Considering the child’s apparent abilities to learn, the teaching process was largely directed at parents, as these were seen as being the closest figures to the child since the child depends on them. Some related answers referred to the child’s assumed close bond with their parents, with this associated with respect, trust, comfortableness, sense of security, and protection through parents. Moreover, parents were thought to have the ability to communicate effectively as they can make their child listen to them, and they are able to engage their child in learning better as they know their own child’s preferences and abilities. Some answers were also related to healthcare professionals being strangers to the child, with the young child likely to feel shy, afraid, or intimidated by strangers. Additional answers were related to the parents’ right to teach and also their right to make decisions about their child’s surgery and their educational process.

Alternatively, when the answer to question 1 was that the nurse or healthcare team teach the child, important information was gained. Some respondents focused on a trusting relationship between the nurse and child, and some expressed the expected educational role of nurses and their good communication skills. A few indicated that nurses were more accessible and less intimidating figures than doctors. Some indicated that nurses could establish an educational plan and were more qualified than parents to teach, moreover they had more time than other healthcare professionals for patient education. Finally, the one-on-

one teaching option was identified by some students as a good choice because it would reduce distractions, enable private conversations, and ensure time to clarify any doubts expressed by the child.

For the students who chose booklets to teach, a common explanation was that this would be a good tool to first approach the young child, as booklets can be non-threatening and an effective way to communicate, as they are often made interesting with visuals, figures, and simple content. However, it was clear from the student view that written material cannot be used alone; the teaching process for young children must be supplemented with teaching from a parent, or a nurse or a doctor.

Best educational method to teach a child aged 6 to 11 years. As reported above, two answers were commonly found in relation to teaching children aged 6-11: “One-on-one teaching by a transplant nurse” and “Group classes of children own age by transplantation team.” For those who chose the one-on-one teaching by a transplant nurse, the students often indicated that as the child is older, they would have an enhanced ability to understand and they would have a need for more information, which meant it was best for the nurse to individualize patient education, ensure a safe space, and enable the child to clarify their doubts or ask questions, and also talk about their experiences and feelings about the process. The one-on-one with a nurse option was also chosen as they felt nurses have the knowledge and ability to carry out patient education, and they are the professional care provider who is closest to the child and has developed a personal relationship with them. In addition, the students thought doctors would use medical jargon, making the dialogue difficult for the child to understand, and doctors were a more intimidating figure as compared to nurses.

For those who chose the option “Group classes of children own age by the transplant team,” these students indicated that collective support from other children would be fundamental to learning. Moreover, contact with other children would contribute to their coping, the group could help focus attention during the teaching-learning process, and this format would ensure enough and different knowledge is provided to each child, and with this potentially being provided in an interactive or fun way. Such a strategy would be important for the children to feel comfortable and not “isolated.” The word isolated was present in most of the students’ answers to this question, with many students also pointing out that the presence of other children would make the child feel less alone. Moreover, the nursing students often indicated that children would likely be more comfortable in a group setting with peers, over one-on-one teaching.

Best education method to teach a child aged 12 to 17 years. With regard to this age group, the most common student choice was “One-on-one teaching by the transplant nurse,” followed by “One-on-one teaching by a transplant doctor.” For those who chose nurse educator, their justifications were related to the nursing professional's relationship with the older child as being relevant and in keeping with the primary role of teaching for nurses. The students also reflected that the nurse would be more “human” and “warmer,” as compared to doctors, because doctors were “colder” and “intimidating,” and the students pointed out that the children would therefore listen more attentively to the nurse. In addition, nurses would promote health maintenance and improvement, while doctors are more oriented to illness. The students also recognized that children at this age are more mature, as they are developing

cognitive abilities and their personal self-identity, and so they are more able to participate in decisions about their own health and health care, want to have power over their decisions, and want to be treated as adults. One-on-one teaching was also said to be important because it individualized care, ensured a private space for the child who may struggle, and enabled better understanding by each child, while also giving them more independence and autonomy. In contrast, for the students who chose “One-on-one teaching by a transplant doctor,” the justifications were largely related to the child possibly having doubts about the surgical procedure itself and so it would be best if they directly talked with the person who would be performing the procedure. In this way, they could obtain or clarify needed information.

Discussion

This study was undertaken to gain insight into organ transplant education for children of three age groups. The results show that nursing students vary in their views about how best to educate children, with this variance a factor of their own age and thus potential stage of adult development. This is an important consideration, as undergraduate nursing course discussions about organ donation and transplantation are not common (Cerrato et al., 2017). Helping students gain teaching skills and abilities is a key function of nursing education, with baseline understandings of organ donation and transplantation needed.

The diversity of findings and justifications of the students also reveal a need for research on the best way to educate children, and particularly those under the age of 6. This is a very special age group, particularly when these young children are compared to children aged 12-17, who have progressed to having the ability to understand complex information. Moreover, 12-17 year-olds typically want and need greater control over their treatment choices. For older children, the health professional was commonly viewed as the most relevant educator, while for younger children the parents were most commonly viewed as the most relevant educator. This method could place young children at risk of inadequate preparation and their parents at risk of moral distress over being the agent of education and treatment options.

For children aged 6-11, both “One-on-one teaching by a transplant nurse” and “Group classes of children own age by transplantation team” were considered equally relevant educational methods. These options demonstrate an understanding that while age is a key consideration for education, individual children at this age may vary in relation to how they can best be educated.

These three age ranges and corresponding differences in educational options by age reflect highly traditional or expected approaches. Child development theories, many of which were developed in the 1960s, such as Piaget’s work, divide children into the three distinct age groups. As such, children under the age of 6 are often depicted as incapable of abstract thought and thus incapable of comprehensive thinking. However, the learning needs and abilities of children who have lived with a chronic disease and its treatment for a few years may not be similar to the age-related child development stages identified by Piaget (Manworren & Woodring, 1998).

Children who have been ill and hospitalized frequently and thus cared for by professional nurses and other adults are not the same as children who have been well and have lived largely separate from the healthcare system and healthcare professionals. Children living with chronic illnesses are likely to have gained considerable knowledge over time about their illness and its treatment, and are likely to have gained the capacity to learn from people other than their parents, such as in classes with other children or through nurses and other healthcare professionals who possess expert knowledge.

As such, children needing organ transplantation at younger ages may have an interest in participating in decision making about their own selves. They may need to be involved in the decision to accept or reject a specific organ, particularly in cases where there is not a perfect match. It is also possible that they need to make the decision about whether to have a transplanted organ or not at all. In these cases, current parental decision-making rights would be curtailed. Research is thus needed to determine the best educational methods for very young children.

Research is also needed to determine at what ages or age young children are capable of participating in decisions, if not solely capable of making major health or healthcare decisions. Courts now are allowing younger and younger children to participate in healthcare decisions, if not outright make them. The case of Makayla Sault, an 11-year-old First Nation girl in Canada, who was given the right by a court to refuse treatment for leukemia, illustrates this socio-legal development (CBC News, 2015). In this case, she had undergone a number of weeks of chemotherapy and then refused more, with her family supportive of her wish to end treatment and possibly die as a result (CBC News, 2015).

Research is also needed to determine why younger nursing students were much more likely to choose parents as the best teachers of young children. It is possible that these are students who cannot yet conceive of life independent of parents. Alternatively, they may be realistic about the best way to teach very young children, having themselves been children recently. However, parents could be disadvantaged if they are no longer considered by older nursing students as being the best or most appropriate educator of their own children. As such, parents could be ignored and disregarded, although they generally continue to have the legal right to make decisions for any underage children and they too have important perspectives on what are acceptable or unacceptable healthcare treatments.

Conclusions

This study identified the views of undergraduate nursing students about the best method to educate pediatric patients of different ages about organ transplantation and ongoing life with a donated organ. Considerable differences in responses were noted, with these responses largely based on the child's age. Some additional differences in findings were based on the student's age and thus potentially their own development life stage. Most compelling among the findings was that it is basically unclear how best to teach chronically-ill children under the age of 6. Although it is commonly thought that very young children cannot comprehend complex material and they need their parents to teach them and make healthcare decisions for them, this study indicates that research should determine how to best educate very young chronically-ill children. These children are different from well children,

Benedetti, C. F. S., & Wilson, D. M.

Age-based Considerations in Educating Children About Organ Transplantation

and so are likely to have different learning needs and abilities.

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Benedetti, C. F. S., & Wilson, D. M.

Age-based Considerations in Educating Children About Organ Transplantation

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