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## Quality of Life and Medical Compliance in the Adolescent Kidney Transplant Population --A Pilot Study

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Quality of Life and Medical Compliance in the  
Adolescent Kidney Transplant Population ---A Pilot Study

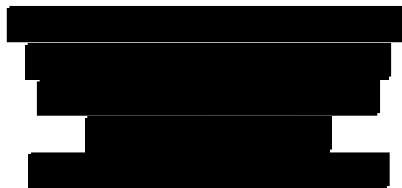
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## Abstract

### *Introduction*

Post renal transplant medical non-compliance is a leading cause of renal graft loss, in the adolescent population. The purpose of this study was to determine if there was a relationship between quality of life and medical compliance.

### *Method*

A pilot study was conducted using a convenience sample of 10 post renal transplant adolescents during their routine transplant clinic appointment. Demographic data was collected and the KINDL Quality of Life questionnaire was completed by study participants. Medical compliance was measured by evaluating transplant clinic appointment attendance, laboratory appointment attendance, and immunosuppressant drug levels.

### *Results*

Despite positive correlations reported in the literature, a negative linear correlation ( $r = -0.7358$ ) was found in this sample between the quality of life score and the medical compliance score.

### *Discussion*

Medication non-compliance remains a major cause of graft failure for the adolescent; a rate that is four times greater than adults. Further study of adolescent behavior, attitudes, and perception of quality of life can assist health care providers in their promotion of medical compliance in adolescents post transplantation.

## Quality of Life and Medical Compliance in the Adolescent Kidney Transplant Population

### Introduction

Every year thousands of people die from organ failure while awaiting donor organs. The demand for organs greatly outnumbers the supply available. Currently there are more than 89,000 people awaiting organ transplants in the United States. Over 2,000 of those waiting are pediatric patients (United Network for Organ Sharing [UNOS], 2005). Receiving these organs saves children's lives and, in most instances, allows them to live a longer, more productive, and healthier life. It is only by careful and thorough follow-up care and medical compliance that transplanted organs last, allowing these patients a chance at a more normal life.

Transplant patients, no matter what the age, face a lifetime of medical challenges. Medications, hospitalizations, clinic appointments, and different medical procedures will consume an organ recipient's life. Coping with these challenges can be especially difficult for the adolescent.

### Medical Compliance

Long-term success of organ transplantation is dependent on medical compliance (Bell, 2000); this has been well documented. There are many definitions in the literature of medical compliance and non-compliance. One of the first accepted definitions of compliance was "the extent to which a person's behavior coincides with medical or health advice." (Haynes, 1979 as cited in Bell, 2000 p. 6) Others explain non-compliance as a term where the patient is at fault in failing to adhere to a treatment regimen judged to be appropriate by medical standards (Wolff, Strecker, Vester, Latta, & Ehrich, 1998). Non-compliance has also been viewed as a behavioral disorder, a self-destructive behavior, and even as an *illness maintaining* behavior (Wolff et al.). The different factors contributing to non-compliance have also been studied. Some significant

contributors that have been identified are: systemic factors such as organization of health care; disease and treatment factors such as the type of disease and the complexity of its treatment; interrelational factors such as rapport and trust between medical staff and patients; and patient and family factors such as health beliefs and quality of coping (Wolff et al., p. 704 table 2)

Non-compliance studies have been completed in both the adult and pediatric populations. To understand non-compliance in the adolescent population it is important to understand adolescent development. Adolescence, alone, is a stressful developmental process even for healthy teens. Chronic illness occurring during adolescence further complicates adolescent development. The chronic disorder, treatment requirements, hospitalization, and surgery all deepen concerns about physical appearance, interfere with the process of gaining independence, and disrupt changing relationships with parents and friends. Adolescent developmental issues complicate a teen's transition toward taking responsibility for managing their illness and learning to comply with recommended treatment. Adolescents who are faced with a chronic illness, such as renal transplant, have an even more difficult time with normal developmental milestones. Body image issues are common during this period, and a chronic illness can intensify these with regard to surgical scars and medication side effects. Chronic illness can interfere with developing independence. This is a time when the adolescent is striving for independence from parents, but is continuing to find themselves relying on them. Their relationship with their peers is also in jeopardy. Chronic illness and its treatment may interfere with schooling and subsequently with time spent with peers. For the healthy adolescent, these years of development can be difficult, and for the chronically ill adolescent it can be even harder with more obstacles to overcome.

Advances in health related technology have greatly increased the survival rates of children and adolescents with chronic illness. This increase has meant that a growing number of

children with chronic disease, who previously would have died, are surviving into adolescence and adulthood. For many of these young people, the challenge of living with their illness can be overwhelming and lead to poor psychosocial functioning and high levels of distress (Rosina, Crisp, & Steinbeck, 2003). With these developmental issues and chronic illness obstacles, it is easy to understand why post kidney transplant non-compliance is one of the leading causes of graft loss in the adolescent population.

### **Consequences of Non-compliance**

The Scientific Registry for Transplant Recipients reported a 5 year allograft survival rate in adolescents of 55% for deceased and 72% for living donors. This represents the worst outcome among kidney transplant recipients of all ages (The Scientific Registry for Transplant Recipients [SRTR], 2004, chap. 5, table 5.8a, c).

Several studies have demonstrated that the adolescent age group is at a very high risk for medical non-compliance. Shaw, Palmer, and Sarwal (2003) studied non-compliance in pediatric renal transplant recipients. This typological study had two major goals. The first goal was to document the rate of non-compliance in a population of pediatric renal transplant recipients. They examined the relationship between chronological age, non-compliance, comorbid psychiatric illness, and the outcome variable of acute and chronic rejection and graft loss. The second goal was to describe and rate the primary reason for non-compliance based on physician report. The researchers found that 32.5% of the subjects studied had clinically significant non-compliance. They also found that the non-compliance was related to the presence of comorbid psychiatric illness. Adolescents had significantly higher rates of non-compliance as well as shorter intervals between transplant date and onset of non-compliance when compared with

younger pediatric patients. This study suggested prevalence rates of non-compliance between 30 and 70% among adolescents (Shaw et al, 2003).

Other researchers concur that the impact of non-compliance is considered far more powerful in adolescent transplant recipients than in the transplant population as a whole (Rianthavorn & Ettenger, 2005, p. 399). Medication non-compliance was identified as the cause of graft failure in over 12% of adolescent patients, which was a rate that is four times greater than adults (Cecka, Gjertson, & Terasaki, 1997). A large children's hospital in southern California reported the incidence of non-compliance with regards to their immunosuppressant medications, was 53% in adolescents compared to only 17% in the younger population (Rianthavorn & Ettenger, p. 399).

Studies on adolescent non-compliance have focused mainly on developing non-compliance theory based on the consequences of non-compliance and what factors lead to non-compliance in the adolescent population. These studies have discussed the factors, such as the quality of the family environment and psychosocial issues, but have not discussed solutions to this problem. Research is needed to explore the adolescent perspective of transplantation and how they perceive their after care. Understanding the adolescent patient and how they view transplantation and perceive their quality of life to be, may help the medical team develop techniques to assist this population in becoming more proactive in their post transplant care.

### **Quality of Life**

The possibility of improving quality of life is the main reason many choose to undergo a transplant (Christensen, Ehlers, & Bertolatus, 2000). Health related quality of life can be seen as encompassing multiple aspects of health related issues from the patients' perspective, including physical, psychological, and social functioning and over all well being (Revicki et al., 2000).

Despite multiple definitions of quality of life, health related quality of life has been defined as the overall status of a combination of many different factors, such as a person's health, symptoms, and level of physical and social functioning. If an illness and its treatment have a negative impact on a person's sense of well being and ability to perform daily activities, then quality of life may be poor (Stedman's, 2000). Quality of life has also been explained to have many components with one of the most important being that it is patient centered, including the outcomes that are relevant from the patient's perspective rather than the physician's (Koscik et al., 2005). Quality of life also includes patients' subjective assessment of the "impact of dysfunction associated with an illness or injury, medical treatment, and health care policy." (Spieth & Harris, 1996).

Koscik et al. described 3 types of quality of life instruments. The first being utility measures, the second being generic or health profiles, and the third being disease specific measures. Utility measures were designed to facilitate comparison of treatments and evaluations of the impact of various diseases. The generic instruments assess dimensions of health related quality of life for a wide range of diseases, and are usually easy to administer. The third type is the disease specific measure which is useful in longitudinal studies examining the effectiveness of treatments (Koscik et al., 2005).

### **Quality of Life and Renal Transplants**

Luk (2004) completed a study based on exploring health related quality of life of Chinese kidney transplant patients in Hong Kong. Results showed that patients were complying with medication regimens and medical recommendations. Although the participants described new symptoms related to the medication regime, they commented that they improved markedly after



transplant in physical and social functioning, and have a better quality of life as a whole (Luk, 2004).

Fiebiger, Mitterbauer, and Oberbauer reviewed health related quality of life after renal transplantation and concluded that even though there are few studies published on health related quality of life after transplantation, the ones that have been completed yielded similar results. Subjects reported that their health related quality of life improved post-transplant, compared to dialysis. It also showed that physical activity, energy, and appearance are important domains that are influenced by the immunosuppressant regimens (Fiebiger et al. 2004).

Medical non-compliance appears to be a major obstacle to the success of adolescent transplantation and medical compliance may be influenced by many different factors. Individual perception and beliefs influence medical compliance. If adolescents believe that their medical regime is essential for good health, they may be more likely to follow medical instructions. The purpose of this pilot study was to determine if there was a relationship between quality of life and medical compliance in the post-transplantation adolescent kidney patient.

## **Method**

A quality of life questionnaire was completed by adolescent kidney transplant patients and their scores on this questionnaire were compared to a medical compliance score that was based on immunosuppressant drug levels, attendance at clinic appointments, and consistency in keeping laboratory appointment blood draws. A medical record review provided demographic and clinical data.

## **Subjects & Settings**

The convenience sample was selected for this pilot study using current patients followed by the kidney transplant program at a large metropolitan children's hospital in Northern California. . Adolescents seen by the medical team in the clinic setting, were invited to participate in the study. Participants were adolescent kidney transplant recipients between the ages of 13 and 21 years, on either Tacrolimus or Cyclosporine, and had a functioning renal graft for at least 6 months. This study was reviewed by all appropriate agencies and met all criteria from their respective institutional review boards. Participant names and clinic appointment schedules were obtained from the kidney transplant program

## **Research Procedure**

Participants were asked to complete the KINDL Quality of Life questionnaire (Ravens-Sieberer & Bullinger, 1998) The KINDL questionnaire consists of 24 Likert-scaled items associated with 6 dimensions: physical well being, emotional well being, self-esteem, family, friends, and everyday functioning. For the adolescents who participated in the study and returned the questionnaire, a chart review was completed and demographic data were obtained. In addition, data were collected related to blood levels of immunosuppressive medications, clinic attendance, laboratory attendance, rejection episodes, and time passed since transplant. The data assembled is shown in Table 1. Scores were computed for both quality of life and medical adherence, and correlations were determined.

Scoring for the quality of life questionnaire was completed as directed by the KINDL questionnaire manual (Ravens-Sieberer & Bullinger, 1998). Scoring for medical adherence was analyzed using three separate areas; clinic appointment attendance, laboratory appointment attendance, and immunosuppressant drug level targets. Chart reviews were conducted to gather

data. The first review included a percentage of attendance of scheduled clinic appointments, the second review included a percentage of attendance of scheduled laboratory appointments and the third review included an average of the immunosuppressant drug levels compared to the target drug level. Each area reviewed was given a percentage score. Once the scores were determined, the three core scores were averaged to give one average compliance score. These scores were used to calculate the correlation between medical compliance and quality of life.

### **Results**

The average age of the subjects was 16.3 years with an average of all subjects being 32 months post transplantation. Sixty percent of participants were male; 40% were female. Six out of ten study patients were maintained on steroid free immunosuppression, while the remaining four were steroid based (see Table 1). When the final statistical calculations were completed the correlation between quality of life and medical compliance showed a negative linear correlation (see Figure 1). The  $r$  value of  $-0.7358$ , indicated a moderate negative correlation. The coefficient of determination  $r^2$  of  $0.54145$  showed 54% of the variance is explained by the linear equation. The average medical compliance score of all the study patients was 86.2% compared to the average quality of life score of 67.5%.

### **Study Limitations**

This study was limited by the small sample size, the fact that it was a convenience sample, and that it was from just one hospital's experience.

### **Discussion**

The purpose of this study was to determine if there was a relationship between quality of life and medical compliance in the adolescent. The literature to date implied a consistent positive correlation i.e., *the higher the Quality of Life, the higher the Medical Compliance*. The results in

this study showed a correlation, however the direction of the considerably different. Many questions have arisen. Why, in this small sample, was there a negative correlation between Quality of Life and Medical Compliance? We are unable to assume from this study alone if the adolescent believes their quality of life is less because they are more compliant with their medical care leading to a more strict and regimented lifestyle. These adolescents believe their quality of life to be better because they feel they have more freedom to *not* follow medical advice. Is the support team too overbearing for the more compliant adolescent, leading to the higher compliance score but the lower quality of life score? It is beyond the scope of this study to address these and many other questions that have arisen from the results. Is the non-compliant adolescent support system lacking, leading to lower compliance but feelings of more independence and freedom, leading to the higher quality of life score? Whatever the answers, it is clear, that quality of life post kidney transplant in this small pilot study is not high, an average score of 67.5% with the average score for compliance in this study being 86.2%.

The results of this study may help to guide future studies on this subject. A multi-centered study with a larger sample size would be essential to determine similar results and any generalizability. A qualitative assessment of this area may further help to uncover themes and common issues about how the adolescent populations feel about life after transplantation. Educational levels also influence medical compliance. Both the adolescent and parental education levels must be taken into consideration when teaching is completed regarding transplantation and follow up care. Looking further into the subject of quality of life, it may be helpful to study and compare the adolescent quality of life pre and post transplantation, giving the medical teams different views when dealing with medical compliance.

Medical compliance can be influenced by many different factors and quality of life is one of these factors. By studying the adolescent perception of their quality of life, the medical team may uncover much needed steps to increasing compliance. There are other factors as well as quality of life that can be taken into consideration to help increase compliance. Individual perception and beliefs can influence these patients and their families. It may help to increase compliance if the adolescent believes and understands that the medical regime is important in keeping themselves healthy, they may be more apt to follow medical instructions. Increasing education for both the patient and their families, increases awareness of the disease and importance of medications and follow up care. In addition, the adolescent's support system can play a very large part in their medical care, compliance, and in their quality of life. If they do not have the support system to help with their care or to help guide them, the adolescent transplant patient may lose focus and forget, or even ignore the medical regime recommended to them.

Creating an adolescent transitional clinic, specifically for this population, may be a way for medical teams to improve long term outcomes. This type of clinic would help the adolescent to transition into young adults, fostering independence with the hope of improving compliance and quality of life. This would be a time for the medical team to educate, listen and encourage responsibility, all the while being able to follow the care of these patients closely. Physicians, Nurse Practitioners, Nurses, social workers psychiatry and child life specialists play important roles in this environment.

### **Conclusion**

The immediate need to increasing compliance in the adolescent kidney transplant population is of extreme importance to their long term health outcome. Medical teams cannot simply focus on medical compliance, they need to take a closer look at the complexity of the

adolescent, and how they view their quality of life after transplant. The ultimate goal is to identify new strategies to help to advance long term outcomes in the adolescent transplant population allowing them to transition to adulthood.

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Table 1

## Summary of Data (n=10)

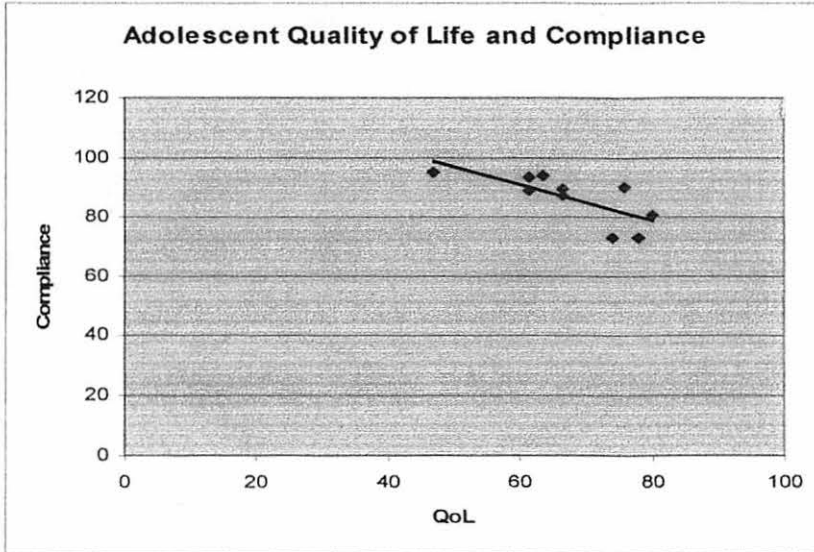
ID	x = QoL Score	y= Med Compliance Score	Immunosuppression	Gender	Age
90001	73.96	72.67	Steroid Free	M	16.6
90002	78.13	72.33	Steroid Based	F	20.4
90003	66.67	87.33	Steroid Free	M	15.3
90004	46.88	95	Steroid Free	M	17.3
90005	61.46	88.67	Steroid Based	F	16.3
90006	76.04	89.67	Steroid Free	F	15
90007	66.67	89.33	Steroid Free	M	14.1
90008	80.21	80.33	Steroid Based	M	15.3
90009	63.54	93.67	Steroid Based	M	17.3
90010	61.46	93	Steroid Free	F	15

*Note: x = Quality of Life Scores; y = Medical Compliance Score; Treatment = Steroid Free or*

*Steroid Based; Gender; 60% male, 40% female*

Figure 1

Adolescent Quality of Life (QoL %) and Compliance (%)



$$y = a + bx$$

$$a = 127.2783562$$

$$b = -0.6085502085$$

$$r^2 = 0.5414458213$$

$$r = -0.735830022$$

## Abstract

### *Introduction*

Post renal transplant medical non-compliance is a leading cause of renal graft loss, in the adolescent population. The purpose of this study was to determine if there was a relationship between quality of life and medical compliance.

### *Method*

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