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Determining the Correlation Between Hemoglobin Levels and the Quality of Life of Adolescents and Young Adults on Hemodialysis: A Descriptive Correlational Study

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DETERMINING THE CORRELATION BETWEEN HEMOGLOBIN LEVELS AND
THE QUALITY OF LIFE OF ADOLESCENTS AND YOUNG ADULTS ON
HEMODIALYSIS: A DESCRIPTIVE CORRELATIONAL STUDY.

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science in Nursing

By

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Abstract

Background: End stage renal disease is a permanent condition where the kidneys are unable to function at a level acceptable to sustain life. Dialysis or kidney transplantation are some of the treatments available to maintain patients' health and well-being. The prevalence of adolescent and young adult patients living with end stage renal disease (ESRD) is increasing. According to the United States Renal Data System (2013), there are over 7,500 patients ages 19 years or younger with ESRD. More than 1,400 of these patients are receiving hemodialysis, this is a national increase of 10.1% for this age group from 2000 (USRDS, 2013). According to Network #9 (Ohio, Indiana, and Kentucky) of The Renal Network (2013), in 2012 there was 138 patients newly diagnosed with ESRD aged 0-24 years. Network #9 also reports 346 ESRD disease patients receiving hemodialysis as treatment for their disease. Many factors such as anemia, fatigue, and treatments have been studied and identified as having an impact on quality of life in adults. But these factors have not been studied in relation to ESRD and its treatment and the impact on an adolescent's and young adults' quality of life (QOL). One of these factors is anemia identified as decreased hemoglobin levels. Decreased hemoglobin levels have been associated with decreased energy level and fatigue which can affect quality of life. Exploring hemoglobin levels and their effect on the quality of life of adolescents and young adults is important, as adolescence is a stressful time regardless of health status.

Objective: The purpose of this study was to explore how the quality of life of adolescents and young adults (age 13-23) receiving hemodialysis for treatment of end stage renal disease have been affected by their disease and treatment. This research study sought to examine the correlation between hemoglobin levels during treatment and patients' perceived fatigue levels and quality of life. The research question which was being asked

was: Do higher hemoglobin levels correspond to a perceived higher quality of life in adolescents and young adults?

Method: The PedsQL™ End Stage Renal Disease Module version 3 Teen Report questionnaire was used to evaluate the perceived QOL of those patients receiving hemodialysis at Cincinnati Children's Hospital Medical Center (CCHMC). A retrospective audit of questionnaires and hemoglobin levels was completed on patients between the ages of 13-23 from October 1, 2011 to September 30, 2013. Means and standard deviations were obtained on hemoglobin levels, fatigue scores and quality of life scores. A Pearson's R coefficient was used to determine if a correlation exists between hemoglobin levels and a patient's perceived QOL.

Relevance: Understanding quality of life and factors influencing QOL is relevant to nurses and other practitioners in order to provide holistic care to their patients. Nurses need to understand the common factors and then assess each individual to determine if these factors exist for their patients. In this way the nurse can address these factors and implement strategies to help improve their patients QOL while they are undergoing hemodialysis for their ESRD.

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Chapter 1- Introduction and Literature Review

Introduction

Chronic renal disease is a progressive and irreversible reduction of renal function in which kidneys are unable to keep metabolic and fluid balance in the body, (National Kidney Foundation, 2013). Patients with end stage renal disease (ESRD) need many forms of treatment and at some time in their disease progress may eventually need renal replacement therapy. Choices for renal replacement therapy include kidney transplantation, hemodialysis or peritoneal dialysis. Of these therapies, hemodialysis is the most commonly used. Both the disease process and the renal replacement therapy can have an effect on the patient's quality of life.

According to the United States Renal Data System (2013), there are over 7,500 patients ages 19 years or younger with ESRD. More than 1,400 of these patient are receiving hemodialysis, this is a national increase of 10.1% for this age group from 2000 (USRDS, 2013). The Renal Network is a national not-for-profit organization which monitors quality of dialysis care. Network 9 monitors states of Indiana, Kentucky, and Ohio. The Renal Network reports that in Network 9 there has been an increase of 138 patients, aged 0-24, newly diagnosed with Chronic End Stage Renal Disease in 2012. Network 9 also report 346 patients aged 0-24 are receiving hemodialysis as treatment for their disease.

The impact of ESRD and its treatment on an adolescent's and young adults' quality of life (QOL) has not been well studied. Exploring the responses of adolescents is important, as adolescence is a stressful time regardless of health status, due to the changes which are occurring with physical maturation, brain development, increased peer interactions and drive for independence (Casey, Jones, Levita, Libby, Pattwell, Ruberry,

Soliman, & Somerville, 2010). While QOL has been studied in the adult population receiving hemodialysis little has been done in the area of adolescents and young adults. Due to an increasing number of adolescents and young adults with ESRD who are receiving hemodialysis issues of QOL need to be evaluated. The purpose of this study was to begin to fill this gap by focusing on the adolescent and young adult population.

An individual whose life is dependent on hemodialysis may have their whole life situation disrupted because of frequent trips to the dialysis unit for maintenance hemodialysis, frequent laboratory procedures, dietary restrictions and medication therapy (Clarkson & Robinson, 2010). These factors may also cause many concerns and stress for adolescents and young adults (Baskale & Baser, 2011). Baskale and Baser also identify “physical activity limitations because of fatigue” (2011, p. 420). One of the contributing factors to fatigue may be anemia or decreased hemoglobin levels. Ziegert, Fridlund, & Lindell (2009) noted the time restrictions are a common concern because of the travel time to and from the dialysis unit and time spent on the dialysis machine, which can be 3 to 4 hours for each treatment, 3 to 4 times per week.

The purpose of this research study was to determine the impact the disease process and treatment may play on the quality of life of adolescents and young adult patients living with end stage renal disease. This was to be accomplished by evaluating hemoglobin levels and patients reported fatigue and quality of life and determining any possible correlations. It is hoped by understanding adolescents’ and young adults perceptions, this information can help nurses to provide care which contributes to the improvement of their quality of life.

Literature review

A literature review was conducted using CINAHL, Cochrane and Medline. Peer reviewed articles within the last 10 years were included. Key search words included hemodialysis, dialysis, renal replacement therapy, end stage renal disease, chronic kidney disease, adolescents, and quality of life.

Incidence and Prevalence

According to the United States Renal Data System (2012) the five year survival rate is 34% for individuals on hemodialysis. According to DaVita (2014), hemodialysis is the process of mechanically cleaning the blood. The blood is removed from the body, via a central venous catheter or vascular access, and circulated through a dialyzer. During this process, the blood is filtered through a semi-permeable membrane which removes waste products and excess fluid, and electrolytes are balanced. The clean blood is then return to the body. Other potential treatments for ESRD include peritoneal dialysis and kidney transplantation. Kidney transplantation offers patients with end stage renal disease the “greatest potential for increased longevity and enhance quality of life” (Griva, 2012, p. 813). Yet many patients do not qualify for transplantation due to recent cancer, untreatable heart disease or psychiatric illness, active substance abuse or compliance with current dialysis treatments (Barnes-Jewish, 2014).

There is evidence in the literature which shows living with a chronic and life threatening illness impacts one’s quality of life (Schick Makaroff, 2012). One of the common themes in the literature related to ESRD is living with the restrictions which accompany kidney failure (Clarkson & Robinson, 2010, Bayhakki & Hattakit, 2012 & Kastouni, Sarantopoulou & Alivannis, 2010). Restrictions focus on time required for dialysis, restrictions on diet and fluids, dependence on caregivers, inability to go to school,

work, or travel and medical costs. These restrictions have been noted as being associated with a lower quality of life in adults. Griva (2012) acknowledges these restrictions were used to sustain life and maintain optimal health to provide the patient with the best chance at receiving kidney transplantation. Hagren, Pettersen, Lutzen & Clyne (2005) stated that “suffering was related to the sense of loss of freedom, dependence on the hemodialysis machine as a life-line, and reliance on caregivers” (p. 295). Schick Makaroff (2012) acknowledges many chronic illnesses can cause fatigue and this is not exclusive to ESRD. In addition to chronic illnesses, there are many other causes of fatigue and anemia is just one of those causes.

Hemoglobin and anemia

As kidney function deteriorates, so does its ability to produce erythropoietin, which results in anemia (Clarkson & Robinson, 2010, Koshy & Geary, 2008). Anemia is defined as a hemoglobin level less than 12.1 g/dL for females and 13.8 g/dL for males (NKF KDOQI, 2006). Erythropoietin is produced in the kidneys and responsible for stimulating red blood cell production (Koshy & Geary, 2008). The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI) recommends the hemoglobin target for ESRD patient be 11.0-12.0 g/dL (2007). This is lower than the recommend level for healthy females which is 12.1-15.1 g/dL, and males which is 13.8-17.2 g/dL. This recommendation was established by NKF KDOQI (2007) because of the associated risk of increase morbidity and mortality and risk of cardiac events seen with higher hemoglobin levels in adults. They also acknowledge the evidence of increase risk of cardiovascular death and coronary artery calcification in children although there are no current studies including adolescents and young adults. According to Koshy & Geary, (2006) hemodialysis patients are also at risk for iron deficiency anemia due to chronic blood loss.

This blood loss is from repeated blood sampling, blood loss through the dialyzers and tubing and the shortened life span of the red blood cell.

Anemia and quality of life

The most common symptom of anemia is fatigue (National Heart, Lung, and Blood Institute, 2012). Jhamb, Weisbord, Steel, & Unruh (2009) found that fatigue is the most common complaint of patient receiving long term renal replacement therapy with an occurrence as high as 60-97% of patients with 94% of patients willing to receive additional treatments if there would be an associated increase in energy level (Jhamb et. al., 2009). Fatigue in dialysis patients can be multi-factorial. Some of the factors contributing to fatigue can be “anemia, malnutrition, uremia, dialysis inadequacy, hyperparathyroidism, coexisting chronic disorders, sleep disorders, depression, side effects of medication, dietary and fluid restrictions and physical inactivity” (Jhamb et. al., 2009, p. 355). Fatigue impacts the daily activity of dialysis patients (Bossola Vulpio & Tazza, 2011). Bossola, Vulpio and Tazza (2011) found fatigue to be is one of four symptoms which can deteriorate the quality of life, the others being pain, lack of well-being and depression. End stage renal disease and its treatment may have a significant impact on the quality of life affecting a patient’s social and psychological well-being (Anees, Hameed, Mumtaz, Ibrahim, & Khan, 2011). Although there are many contributing factors, this study examined the relationship between anemia as evidenced by hemoglobin levels and stated fatigue scores and quality of life.

Conclusion

There are a significant number of adolescents and young adults with end stage renal disease. Many of these adolescents and young adults are replacing the kidney function and maintaining their health with hemodialysis. End stage renal disease and it

treatment of hemodialysis contributes to and increase risk of a low hemoglobin. Low hemoglobin or anemia is related to an increase in fatigue and which can affect the quality of life. Most research has focused on quality of life of adults. There is a gap in the literature related to the adolescent and young adult population of hemodialysis. With a growing population of adolescents and young adults living with end stage renal disease, research needs to be expanded to include this population. This study hoped to begin to fill this gap by focusing on adolescents and young adults.

Chapter 2 - Theoretical Model

Wilson and Cleary (1995) developed a model to describe the relationship between patient outcomes and health related quality of life. The model was developed to show the different health domains which all have an impact on affecting health related quality of life relationship. At the time this model was developed Wilson and Cleary did not believe there was a model that described the relationship between clinical variable and health status measures. They developed this model to bridge this gap.

Ferrans, Zerwic, Wilbur and Larson (2005) (Figure 1) modified the original Wilson and Cleary model to clarify the elements of health related quality of life and the relationships among them. According to this model, there are four domains which combine to affect overall quality of life. These domains are: biological function, symptoms, functional status, and general health perceptions. Characteristics of the individual and of the environment influence all of these determinants as well as quality of life. Characteristics of the individual are categorized as demographics, developmental, psychological, and biological factors that influence health outcomes (Ferrans et. al., 2005). These characteristics include sex, age, ethnicity, cognitive process, and genetically linked characteristics. For the purpose of this study, characteristics of the individual obtained were age, race and sex. Characteristics of the environment are described as social or physical factors in the person's life which affects health. Environment characteristics include, marriage or family status, social, culture and neighborhood. Environmental characteristics were not evaluated in this study.

Wilson and Cleary's (1995) model included factors of biological and physiological variables, symptoms, functional status, and general health symptoms leading to overall quality of life. Characteristics of the environment and of the individuals affect all the

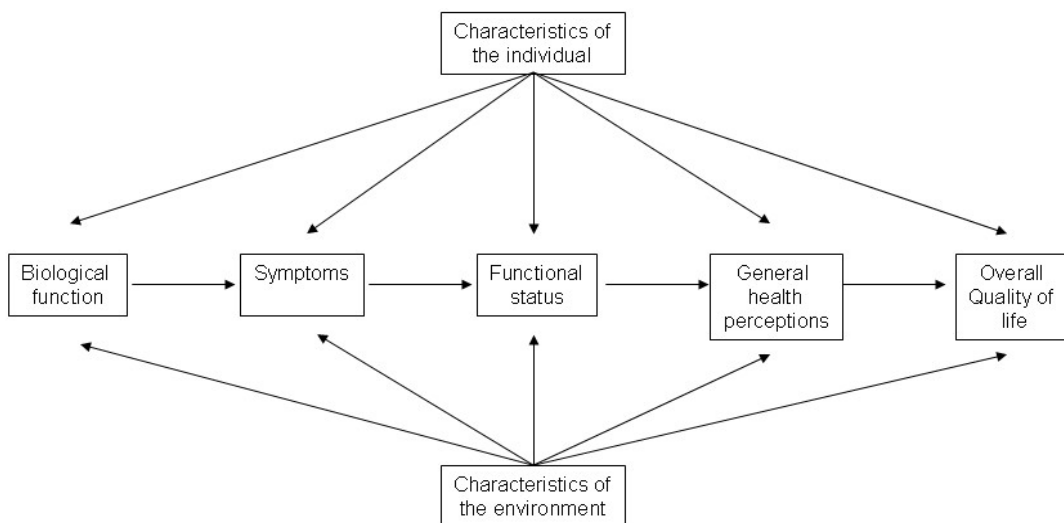


Figure 1. Ferrans, C., Zerwic, J., Wilbur, J. Larson, J. (2005). Conceptual model of health-related quality of life

domains related to quality of life except the biological and physiological variables. The biological and physiological factors were shown to only affect the overall quality of life, but did not have an influence on. The arrows leading to each of the factors are labeled. Non-medical factors were included but only showed effect on the overall quality of life. The revised version showed the characteristics of the environment and characteristics of the individual as also affecting the biological function. The non-medical factors were eliminated because these factors were thought to be included into the characteristics of the individual or environment. The labels on each of the arrows were removed because it may be limiting. Ferrans et. al. (2005) also recognized that although the arrows are pointing one direction, they can be reversed showing effect in either direction. While this study is looking at one of the factors which may influence quality of life, there are many other factors which play a role in overall quality of life. Ferrans et. al. (2005) model was chosen for this study because it was all inclusive in the multiple factors which can influence an adolescent and young adult's quality of life.

Domains:

Biological function includes the dynamic processes which supports life (Ferrans et. al., 2005). Biological function comes from metabolism of cell and organ systems and can be measured with laboratory test, physical assessments and medical diagnoses. Alterations in biological function can impact all the subsequent determinants of quality of life. For this study biological function was measured by laboratory documentation of serum hemoglobin levels obtained through chart audits.

The next domain of the revised Wilson and Cleary model is symptoms. Symptoms are defined as “a patient’s perception of an abnormal physical, emotional, or cognitive state, which can be categorized as physical, psychological or psychophysical” (Ferrans et.al., 2005 p. 339). Symptoms are related to biological function but they can be different in individual patients with the same disease. For this study the symptom assessed was fatigue and was measured by the results of the General Fatigue section of the PedsQL™ End Stage Renal Disease Module version 3 Teen Report.

Functional status is the next domain. According to Ferrans et. al. (2005) functional status has been defined broadly as the ability to perform tasks. These domains of functioning are often measured as physical function, social function, role function, and psychological function. Functional status is often influenced by biological function and symptoms. Functional status was not evaluated in this study.

The next level of the model is general health perceptions. Ferrans et. al (2005) describes general health perceptions are a representation of all health concepts together. They are also subjective in nature. This is the level which is typically measured with a Likert scale ranging from poor to excellent.

The final component of the model is overall quality of life. Wilson and Cleary (1995) characterized this as how satisfied or dissatisfied someone is with different aspects of life that are important as a whole. Quality of life is subjective and individualized. For the purpose of this study the overall score of the PedQL™ End Stage Renal Disease Module version 3 Teen Report was considered to be the patients' quality of life.

The model depicts a one direction flow of influencing factors toward quality of life. However the author acknowledges these arrows only represent the typical pathway, but it is probable that any arrow could point the opposing direction representing the complexity of the interactions between the various factors affecting quality of life.

Overall quality of life is a person's sense of overall satisfaction or dissatisfaction of areas of their life that is important to them (Ferrans et. al., 2005). Many factors contribute to adolescents and young adults with ESRD treated with hemodialysis overall quality of life. One of the factors in the biological domain is the hemoglobin levels and one of the factors in the symptom domain is fatigue. Therefore the purpose of this study was to evaluate the effects of hemoglobin level and fatigue on the overall quality of life.

Chapter 3 – Methodology

The purpose of this study was to look at the correlation between hemoglobin level and fatigue and its effect on the overall quality of life of adolescent and young adults on hemodialysis for treatment of ESRD. Fatigue has been shown to be the most common symptom of decreased hemoglobin, which in turn has been linked to a decrease in a person's overall quality of life. This study was a retrospective chart review of adolescents and young adults being treated with hemodialysis for ESRD at Cincinnati Children's Hospital Medical Center (CCHMC). Hemoglobin levels and scores for fatigue and overall QOL were obtained via chart audit over a two year period.

Approval for the thesis study was obtained from the thesis chair at Cedarville University, Amy Voris D.N.P., RN, CNS, Assistant Professor of Nursing at Cedarville University. Other thesis committee personnel included Cliff Fawcett M.S.N., M.Ed., RN, CFNP, Assistant Professor of Nursing and Jennifer de Klerk M.S.N., RN, CCHMC manager of Pediatric Primary Care Clinic in Fairfield, Ohio. A letter of support (Appendix A) for this study was obtained from Dr. Rene Van De Voorde III MD who is the medical director of the dialysis unit. IRB approval was obtained from Cedarville University (Appendix B) and Cincinnati Children's Hospital Medical Center (Appendix C). The chart audit began January 2014 and was completed February 2014. The data base was created using SPSS[®] and statistical analysis was performed and completed April 2014. Results were presented at Cedarville University in April 2014.

Subjects

The retrospective chart audit was completed from October 1, 2011 to September 30, 2013. The population was patients who have received hemodialysis in the outpatient dialysis unit at Cincinnati Children's Hospital Medical Center. This unit treats infants,

children and young adults from the 0-23 years of age. Due to the fact young adults' ages 19-23 are treated in the child and adolescent environment, the inclusion age was 13-23 years old. Seventeen patient questionnaire and lab values from the same time frame were reviewed. An inclusion criterion was patients with end stage renal disease on hemodialysis, 13-23 years of age. At times, outpatients may have been admitted to inpatient status and then back to outpatients. Therefore questionnaires were missing on several patients due to the fact questionnaires were not obtained during inpatient hospitalizations. Patients less than 13 years of age or patients diagnosed with acute renal failure were excluded.

Design

This is a descriptive correlational study. The researcher reviewed patient demographic information, hemoglobin levels and the PedsQL™ End Stage Renal Disease Module.

Measurement tools

The PedsQL™ End Stage Renal Disease Module version 3 Teen Report (Appendix D) was the questionnaire used for this study. This was the questionnaire currently being used by the outpatient hemodialysis unit. It was developed to evaluate the quality of life of adolescents living with end stage renal disease, including those being treated with hemodialysis. The PedsQL™ End Stage Renal Disease Module Teen version was created for teens 13-18 years of age, however at CCHMC the young adult (19-23) population completes the same questionnaire. The questionnaire has 34 items and uses a 5 point Likert scale. The scale ranges from 0 (never) to 4 (almost always). The questionnaire is composed of seven domains: (1) General Fatigue (4 items), (2) About My Kidney Disease (5 items), (3) Treatment Problems (4 items), (4) Family and Peer Interactions (3 items), (5)

Worry (10 items), (6) Perceived Physical Appearance (3 items), and (7) Communication (5 items). Scoring was accomplished by adding the selected number for each item in a section to give a sub score for that section. The quality of life score was determined by the sum of all the scored items on the questionnaire. Reliability of the PedsQL™, as reported by Goldstein, Graham, Warrady, Seikaly, McDonald, Burwinkle, Limbers, and Varni, “exceeded the minimum reliability standard of 0.70” (2008, p. 288) and construct validity was 0.94. All hemodialysis patients at CCHMC are asked to fill out the questionnaire twice a year, however completing the questionnaire is voluntary. CCHMC has a limited license to use the PedsQL™ only for clinical purposes. Hemoglobin values were collected corresponding to the date each questionnaire was collected. Hemoglobin levels are routinely collected from each patient on a monthly basis. One hemoglobin value recorded just prior to the completion of the questionnaire was collected. Demographic information collected included age, sex, and race.

Procedure for data collection

A retrospective chart audit from October 1, 2011 through September 30, 2013 was completed. Values for hemoglobin levels were obtained from the patient’s electronic medical record. Hard copy of the PedsQL™ End Stage Renal Disease Module version 3 Teen Report (ages 13-18) was reviewed. The score for each question on the questionnaire was collected as well as the total score. A subtotal of the General Fatigue section was also calculated. A total of forty-seven questionnaire were reviewed. Nine of those questionnaires were missing more than fifty percent of the scores for the questions. Therefore those 9 questionnaires were excluded from the total quality of life and hemoglobin correlation. All forty-seven questionnaires contained completed scores for the

General Fatigue section therefore all forty-seven questionnaires were included in the general fatigue and hemoglobin correlation.

Data analysis

Mean and standard deviation of patient demographics, hemoglobin level, and general fatigue score and overall quality of life score were calculated. Pearson's correlational was run between hemoglobin levels and quality of life score, and hemoglobin level and general fatigue sub score.

Ethical considerations

Patient data was coded and each patient was designated by a number. Only the principal investigator had access to each patient name in relation to the number assigned. Data was transcribed to a paper form. This paper included only the patient number and did not include any patient identifiers. Social workers from the dialysis unit at CCHMC gave the questionnaires to the parents of patients under 18 years of age. Consent was assumed when questionnaires are completed and returned to the social worker. As this was a retrospective chart audit, consent was not required from patients to be included in this study. Research finding and statistics are reviewed in the next chapter.

Chapter 4 – Results

The purpose of this study was to examine the relationship between hemoglobin levels and general fatigue and quality of life scores of adolescents and young adults on hemodialysis for treatment of end stage renal disease. This was a retrospective chart audit over a two year time period from October 1, 2011 and September 30, 2013. There were a total of five data collection points: Fall of 2011, Spring of 2012, Fall of 2012, Spring of 2013, and Fall of 2013. A convenience sample was used from Cincinnati Children's Hospital and Medical Center.

The study included 17 patients. Of the 17 patients, there was 6 males (35.3%) and 11 females (64.7%) (Table 1). Ages ranged from 14 to 23 years, (age 14-18, N=11 65%, age 19-23, N=6, 35%) (Table 2). Race included African American (N=6, 35%), Caucasian (N=10, 59%) and Hispanic (N=1, 6%). The total number of questionnaires completed by each patient ranged from 1 to 5 based on admission and discharge from the dialysis unit. Of the 17 patients, 5 patients remain in the unit, 5 patients were transferred to an adult unit, 2 patients moved away from the center, 1 patient was transitioned to peritoneal dialysis, and 4 patients received a kidney transplant (Table 3).

Table 1. Gender of participants

Gender	N= (%)
Male	6 (35.3%)
Female	11 (64.7%)

Table 2. Age of participants

Age (years)	N= (%)
14-18	11 (65%)
19-23	6 (35%)

Table 3. Attrition

Reason for leaving unit	N=
Transferred to adult unit	5
Moved away from center	2
Transitioned to peritoneal dialysis	1
Received kidney transplant	4
Still in unit	5

There were a total of 47 questionnaires. There were nine questionnaires which were missing more than 50% of the data and were not included in the correlation. A 1-tailed Pearson's correlation was ran on the 38 completed questionnaires examining the relationship between the PedsQL™ quality of life total score and the hemoglobin level from the corresponding time frame (Table 4), with a Pearson's r significance of $p < 0.05$. The total score was calculated by taking the sum of the score for the 34 questions on the questionnaire. The total possible score on the PedsQL™ ranged from 0-136, with zero being the best quality of life rating. The scores ranged from 22-97. The mean quality of

Table 4. PedsQL™ total score and Hemoglobin levels

Time	Participants	Hemoglobin Levels	Quality of Life Scores	r	P
	(N)	M (SD)	M (SD)		
Fall 2011	8	11.34 (1.31)	49.13 (22.47)	-0.1	0.41
Spring 2012	10	10.63 (2.23)	50.00 (22.96)	0.21	0.28
Fall 2012	10	10.98 (1.51)	49.70 (22.38)	0.37	0.15
Spring 2013	6	10.30 (1.95)	46.67 (17.24)	-0.29	0.29
Fall 2013	4	11.68 (1.75)	51.50 (9.26)	0.5	0.25

Significance * $p > 0.05$

life scores ranged from 46.67(17.25) to 51.50 (9.26). The mean hemoglobin level ranged from 10.30(1.95) to 11.68(1.75). No correlation was noted between the PedsQL™ total scores and the mean hemoglobin levels.

There were a total of 47 questionnaires, all of these questionnaires contain complete in the General Fatigue section, and therefore all 47 questionnaires were included. A 1-tailed Pearson's correlation was run on the 47 questionnaires examining the relationship between the General Fatigue section sub score from the PedsQL™ and the hemoglobin level from the corresponding time frame (Table 5). The total possible score on the General Fatigue sub score ranged from 0-16, with zero representing fatigue “never”

Table 5. General Fatigue sub score and Hemoglobin levels

Time	Participants	Hemoglobin Levels	General Fatigue Scores	r	P
	(N)	M (SD)	M (SD)		
Fall 2011	9	11.4 (1.24)	7.33 (3.28)	-0.25	0.26
Spring 2012	12	10.84 (2.11)	7.58 (3.09)	-0.2	0.26
Fall 2012	13	11.35 (1.50)	7.08 (3.09)	-0.08	0.40
Spring 2013	8	10.85 (2.33)	5.5 (3.46)	-0.43	0.14
Fall 2013	5	12.04 (1.72)	7.0 (3.46)	-0.77	0.06

Significance *p>0.05

being a problem and 16 representing fatigue as “almost always” being a problem. The scores ranged from 0-13. The mean of the general fatigue sub scores ranged from 5.5(3.46) to 7.58 (3.09). The mean hemoglobin level ranged from 10.84(2.11) to 12.04(1.72). With a Pearson's r significance of p<0.05, a negative weak correlation which was noted but no significance was found. Many factors have been studied in adults with ESRD and its treatment on the quality of life of those patients. Few studies have evaluated factors affecting the quality of life in adolescents and young adults with ESRD receiving dialysis. The purpose of this study was to evaluate one of these factors, anemia, as

evidenced by decreased hemoglobin levels, and its effect on their quality of life. No correlation between the PedsQLTM overall score and mean hemoglobin levels was noted. There was a weak negative correlation between the General Fatigue sub score, but the results were not significant. The next chapter will discuss research needs related to the results obtained from this study.

Chapter 5 - Discussion

There are an increasing number of adolescents and young adults with ESRD who are receiving hemodialysis. The impact of end stage renal disease and its treatment on an adolescent's and young adults' quality of life has not been well researched. Most research in the area of ESRD and quality of life has focused on adults. Exploring the responses of adolescents is important, as adolescence is a stressful time regardless of health status, due to the changes which are occurring with physical maturation, brain development, increased peer interactions and drive for independence (Casey et. al., 2010). Research has shown fatigue to be the primary symptom of anemia or a low hemoglobin level and fatigue may affect one's quality of life. Therefore the purpose of this study was to examine the relationship between hemoglobin levels and general fatigue and quality of life scores of adolescents and young adults on hemodialysis for treatment of end stage renal disease.

Limitations

Many limitations may have affected the results of this study. One of the limitations of this study was the small convenience sample. This small sample may have affected the statistics of this study, with the resulted insignificance noted. Fatigue was the only symptom evaluated by this study as measured by hemoglobin and its effects on quality of life, yet as stated earlier there are many other factors which can affect quality of life. Only one hemoglobin level which was collected prior to the questionnaire was used. Collecting more serial hemoglobin levels throughout the course of dialysis may have shown a correlation. Patient with end stage renal disease often have several other comorbidities which were not evaluated by this study which may have affected a patients perceived QOL. As questionnaires were completed during dialysis treatment, scoring of quality of life may have been affected by the side effects of the treatment that particular day. This

study evaluated only one of many factors which affect overall quality of life and fatigue may not be the sole influence of decreasing quality of life. Each of the many factors which affect quality of life may not be enough to reflect significance alone, however the accumulative effect of all of the factors affect the quality of life.

Future research

Future recommendations for research would be to repeat the same study with the ability to publish the results using the PedsQL™, and repeating the same study with a larger population. The PedsQL™ is only collected twice a year but a more frequent collection may provide a more accurate picture of quality of life. One hemoglobin level prior to the PedsQL™ collection was used to calculate the correlations, but obtaining all hemoglobin level in each time period may have provided a more accurate reflection of hemoglobin level and fatigue. Each factor which may affect quality of life alone may not be enough to significantly affect quality of life, but the accumulating impact of multiple factors may be more significant. Future research could include collecting more frequent PedsQL™ questionnaires and hemoglobin levels. Additional research could also include factors from the other domains which affect quality of life.

Understanding quality of life and factors influencing QOL is relevant to nurses and other practitioners in order to provide holistic care to their patients. Nurses need to understand the common factors and then assess each individual to determine if these factors exist for their patients. In this way the nurse can address these factors and implement strategies to help improve their patients QOL while they are undergoing hemodialysis for their ESRD.

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APPENDIX A



Nephrology & Hypertension

Director

Prasad Devarajan, MD

Business Director

Brian Bain, MBA

Business Manager

Alisa Madden, MA

Sr. Administrative Assistant

Ebony Washington

Faculty

Michael R. Bennett, PhD

John J. Bissler, MD

Bradley P. Dixon, MD

Jens Goebel, MD

Stuart L. Goldstein, MD

David K. Hooper, MD, MS

Elizabeth Jackson, MD

Paul T. McEnery, MD, MBA

Mark Mitsnefes, MD, MS

Edward Nehus, MD, MS

C. Frederic Strife, MD

Rene G. VanDeVoorde III, MD

Administrative Assistants

Kate Bertram, BA

Deb Scott

Amanda Cooper

Maria Hoffman, BA

Medical Assistant

Donna Young

Becky Graf

Renal Nurse Coordinators

Denise McAdams, RN

Janis Kartal RN

Julie Ross, RN

Debbie Schoborg, RN

Myrna Wiedeman, RN

Erin Rairden, RN

Living Donor Coordinator

Marty Hudson, RN

Advance Practice Nurses

Colleen Klosterman, APN

Angel Roudebush, APN

Renal Social Worker

Kori Frost, LISW-S

Sondra Weingartner, LISW

Renal Dietitian

Susan Tulley, RD, CSP, LD

Transplant Coordinator

Holly Millay

CACN Program Administrator

Barbara Logan, BS, CCRP

CACN Program Coordinator

Patti Holshouser, BBA, CAP-OM

CACN Data Coordinator

CACN Fellow

Ahmad Kaddourah, MD

CACN Research Nurse

Theresa Mottes, RN

Operations Coordinator

Jack Lennon, BSBA

Clinical Manager, Dialysis Unit

Christine Roedersheimer, RN

Research Coordinators

Jenna Atkinson, MED

Elizabeth Coombs, RN, BSN

Kim Denier

Cassie Kirby, BA, CCRP

Tara Terrell, BA

Research Nurse

Carrie Schultz, RN

Fellows

Donna Claes, MD

LaTawnya Pleasant-Griffin, MD

Hyunjung Stella Shin, MD

Nianzhou Xiao, MD

Keri Drake, MD

Gilad Hamdani, MD

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September 3, 2013

Carlisa Waldman

Cincinnati, Ohio 45231

Dear Mrs. Waldman,

It is my pleasure to write a letter in support of your proposed research regarding Quality of Life of Adolescent and Young Adult Patients on Hemodialysis, which is being submitted for approval to Cincinnati Children's Hospital Medical Center Institutional Review Board.

The adolescent years can be a challenge by itself and having a chronic disease complicates this crucial time of development. I believe research that explores the quality of life of our pediatric population is important to better understand our patients. This proposed research project will help add to this understanding. I also believe this research is fitting with your years of experience, your strong background in hemodialysis and working with our teen/young adult population.

In conclusion, I fully support you and the dialysis unit in researching the impact that end stage renal disease and hemodialysis has on our patients.

Sincerely,

Rene G. Van De Voorde III, MD
Medical Director, Dialysis Unit

Cincinnati Children's Hospital Medical Center

3333 Burnet Avenue, Cincinnati, OH 45229-3039 | 513-636-4200 | www.cincinnatichildrens.org

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APPENDIX B



Waldman, Carlisa E <carlisawaldman@cedarville.edu>

Re: Proposal to conduct research submission

1 message

Institutional, Review Board <[REDACTED]@cedarville.edu>

Mon, Oct 28, 2013 at 2:28 PM

To: Carlisa Waldman <[REDACTED]@cedarville.edu>

Dear Carlisa,

Your study has been approved to proceed as specified.

Jessicah Zehring

On Thu, Oct 24, 2013 at 9:03 AM, Carlisa Waldman <[REDACTED]@cedarville.edu> wrote:

Your Name Carlisa Waldman

Your Email [REDACTED]@cedarville.edu

Address

Comments Determining the Relationship Between Hemoglobin Levels and Quality of Life of Adolescent and Young Adult Patients on Hemodialysis, A Retrospective Correlational Study

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APPENDIX C

Page 1 of 3

Institutional Review Board - Federalwide Assurance #00002988

Cincinnati Childrens Hospital Med Ctr

Date: 10/18/2013

From: CCHMC IRB Committee

To: Principal Investigator: Carlisa Waldman
OPD Base

Study ID: [2013-5482](#)

Re: Study Title: Determining the Relationship Between Hemoglobin Levels and Quality of Life of Adolescent and Young Adult Patients on Hemodialysis, A Retrospective Correlational Study

The above referenced protocol and all applicable additional documentation provided to the IRB were reviewed and **APPROVED** using an **EXPEDITED** review procedure in accordance with 45 CFR 46.110(b)(1)(see below) on **10/18/2013**.

This study will be due for continuing review at least 30 days before: 10/17/2014.

Study Documents

IRB Protocol 10-15-13 Version 2 Hemodialysis and Quality of Life

Letter of support for research

PedsQL End Stage Renal Disease Module Teen Version

Please note the following requirements:

Consent Requirements

Per 45 CFR 46.116 the IRB has waived the requirement to obtain informed consent for all adult participants.

Parental Permission Requirements

Per 45 CFR 46.116 the IRB has waived the requirement to obtain parental permission from the parent(s) (or guardian) of all child participants. NOTE: If your research is subject to FDA regulations it is not eligible for this waiver of parental permission.

Assent Requirements

Per 45 CFR 46.116 the IRB has waived the requirement to obtain assent from all child participants. NOTE: If your research is subject to FDA regulations it is not eligible for this waiver of assent.

file:///C:/Users/mwaldman/AppData/Local/Microsoft/Windows/Temporary%20Internet%... 10/23/2013

HIPAA Requirements

Per 45 CFR 164.512 the IRB has granted a waiver from the requirement to obtain an authorization for the use and/or disclosure of protected health information (PHI).

AMENDMENTS: The principal investigator is responsible for notifying the IRB of any changes in the protocol, participating investigators, procedures, recruitment, consent forms, FDA status, or conflicts of interest. Approval is based on the information as submitted. New procedures cannot be initiated until IRB approval has been given. If you wish to change any aspect of this study, please submit an Amendment via ePAS to the IRB, providing a justification for each requested change.

CONTINUING REVIEW: The investigator is responsible for submitting a Continuing Review via ePAS to the IRB at least 30 days prior to the expiration date listed above. Please note that study procedures may only continue into the next cycle if the IRB has reviewed and granted re-approval prior to the expiration date.

UNANTICIPATED PROBLEMS: The investigator is responsible for reporting **unanticipated problems** promptly to the IRB via ePAS according to current reporting policies.

STUDY COMPLETION: The investigator is responsible for notifying the IRB by submitting a Request to Close via ePAS when the research, including data analysis, has completed.

Please note: This approval is through the IRB only. You may be responsible for reporting to other regulatory officials (e.g. VA Research and Development Office, UC Health – University Hospital). Please check with your institution and department to ensure you have met all reporting requirements.

Statement regarding International conference on Harmonization and Good clinical Practices. The Institutional Review Board is duly constituted (fulfilling FDA requirements for diversity), has written procedures for initial and continuing review of clinical trials: prepares written minutes of convened meetings and retains records pertaining to the review and approval process; all in compliance with requirements defined in 21 CFR Parts 50, 56 and 312 Code of Federal Regulations. This institution is in compliance with the ICH GCP as adopted by FDA/DHHS.

Thank you for your cooperation during the review process.

Research Categories

5. Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)

APPENDIX D

ID#	_____
Date:	_____

PedsQL™

End Stage Renal Disease Module

Version 3.0

TEEN REPORT (ages 13-18)

DIRECTIONS

Teens with End Stage Renal Disease sometimes have special problems.
Please tell us **how much of a problem** each one has been for you during the
past ONE month by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you ...

GENERAL FATIGUE (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel tired	0	1	2	3	4
2. I feel physically weak (not strong)	0	1	2	3	4
3. I feel too tired to do things that I like to do	0	1	2	3	4
4. I feel too tired to spend time with my friends	0	1	2	3	4

ABOUT MY KIDNEY DISEASE (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I get swelling in my face	0	1	2	3	4
2. I feel dizzy	0	1	2	3	4
3. I get headaches	0	1	2	3	4
4. I get thirsty	0	1	2	3	4
5. I get muscle cramps	0	1	2	3	4

TREATMENT PROBLEMS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to remember to take my medicines	0	1	2	3	4
2. I don't like how I feel after I take my medications	0	1	2	3	4
3. It is hard for me to drink the amount of fluid I'm supposed to	0	1	2	3	4
4. I get upset when I cannot eat foods that I want to eat	0	1	2	3	4

FAMILY AND PEER INTERACTION (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult for me when other people don't understand about my illness	0	1	2	3	4
2. I can't do things with my family because of my treatment	0	1	2	3	4
3. I feel left out of activities with my friends because of my treatment	0	1	2	3	4

In the past **ONE month**, how much of a **problem** has this been for you ...

WORRY (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I worry about whether or not my medical treatments are working	0	1	2	3	4
2. I worry about having surgery	0	1	2	3	4
3. I worry that I will be sick for a long time	0	1	2	3	4
4. I worry that I will have to stay in the hospital	0	1	2	3	4
5. I worry about my blood pressure	0	1	2	3	4
6. I worry that I will get sick if I don't take my medicines	0	1	2	3	4
7. I worry about my weight	0	1	2	3	4
8. I worry about getting infections	0	1	2	3	4
9. I worry about having needle sticks (i.e., injections, blood tests, IVs)	0	1	2	3	4
10. I worry about the results of my blood tests	0	1	2	3	4

PERCEIVED PHYSICAL APPEARANCE (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I don't like other people to see my scars	0	1	2	3	4
2. I don't look as old as other kids my age	0	1	2	3	4
3. I am embarrassed that my medicines will change the way I look	0	1	2	3	4

COMMUNICATION (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to tell other people at the hospital (i.e., child life, dietician, social worker) how I feel	0	1	2	3	4
4. It is hard for me to explain my illness to other people	0	1	2	3	4
5. It is hard for me to tell my parents how I feel	0	1	2	3	4

