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A nurse-led intervention designed to improve compliance for patients receiving hemodialysis

Stephanie N. Mott

A Nurse-Led Intervention Designed to Improve Compliance for Patients Receiving Hemodialysis

by

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A SCHOLARLY PROJECT

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In presenting this scholarly project in partial fulfillment of the requirements for a doctoral degree from The University of Alabama in Huntsville, I agree that the Library of this University shall make it freely available for inspection. I further agree that permission for extensive copying for scholarly purposes may be granted by my advisor or, in his/her absence, by the Director of the Program or the Dean of the School of Graduate Studies. It is also understood that due recognition shall be given to me and to The University of Alabama in Huntsville in any scholarly use which may be made of any material in this scholarly project.

Stephanie N Mott 10/15/17

Student Signature Date

SCHOLARLY PROJECT APPROVAL FORM

Submitted by Stephanie N. Mott in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice and accepted on behalf of the Faculty of the School of Graduate Studies by the scholarly project committee.

We, the undersigned members of the Graduate Faculty of The University of Alabama in Huntsville, certify that we have advised and/or supervised the candidate on the work described in this scholarly project. We further certify that we have reviewed the scholarly project manuscript and approve it in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice.

10-16-2017 L O'Keefe PhD, CRNP
(Date) Committee Chair

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Program Director

College Dean

Graduate Dean

ABSTRACT

The School of Graduate Studies
The University of Alabama in Huntsville

Degree: Doctor of Nursing Practice College: Nursing

Name of Candidate: Stephanie N. Mott

Title: A Nurse-Led Educational Intervention Designed to Improve Compliance for Patients Receiving hemodialysis

There are five stages of chronic kidney disease (CKD). Each stage is determined by the glomerular filtration rate (GFR). A decrease in GFR is indicative of worsening renal failure. End Stage Renal Disease (ESRD) is stage V chronic kidney disease, which according to the National Kidney Foundation KDOQI ™ was defined as a GFR less than 15ml/min/1.73m^2. The development of Stage V CKD in a symptomatic patient necessitates a renal transplant or renal replacement via hemodialysis or peritoneal dialysis. Research revealed that mortality and morbidity increases due to noncompliance in the ESRD population and is a widespread issue in the ESRD population.

Noncompliance in the population of patients receiving hemodialysis is associated with the development of complications such as congestive heart failure, death, and other co-morbidities. It has been demonstrated that limited health literacy increases risks for noncompliance. The purpose of this project was to evaluate how a nurse-led educational intervention, which targets an individual's health literacy level, affects compliance with hemodialysis.

Abstract Approval: Committee Chair Louise O'Keefe PhD, CRNP

Program Director

Graduate Dean

Identification of the Problem

The Kidney Disease Outcomes Quality Initiative (KDOQI) defined Chronic Kidney Disease (CKD) as damage to the kidneys and or decrease in GFR to less than 60mL/min/1.73m^2 for three months (2002). CKD is classified into five stages that are determined by the estimated glomerular filtration rate (GFR), or the estimated amount of blood that passes through the glomerulus each minute. Reduced amounts of blood passing through the glomeruli are indicative of renal dysfunction. According to KDOQI, End Stage Renal Disease (ESRD) is chronic kidney disease stage five, which is a GFR less than 15ml/min/1.73m^2 (2002). This medical condition requires either a renal transplant or initiation of dialysis (peritoneal dialysis or hemodialysis) for symptomatic patients to sustain life. There are over one million patients worldwide, and 593,086 patients in the United States diagnosed with ESRD (Incidence, prevalence, patient characteristics, & modality, 2012). African Americans are 3.5 times more likely to suffer from ESRD than the Caucasian population (ESRD, 2012). Noncompliance with hemodialysis treatments, fluid restrictions, nutrition, and medications are challenges for the ESRD population and can lead to complications such as pruritus, congestive heart failure, hyperkalemia, metabolic bone disease, and death (Baraz, Parvardeh, Mohammadi, & Broumand, 2010).

Missed and shortened (lacking at least 10 minutes of prescribed dialysis) hemodialysis treatments have demonstrated an increase in mortality and hospitalizations (Obialo, Hunt, Bashir, & Zager, 2012). Minority populations, patients aged less than 55 years of age, and those who dialyzed on Saturday were more likely to miss or shorten their hemodialysis (Obialo, Hunt,

Bashir, & Zager, 2012). Inadequate hemodialysis treatments may result in insufficient dialysis; this can lead to other complications such as volume overload, worsening anemia, access thrombosis, and cardiac or cerebrovascular complications.

Research supports interventions to improve adherence among the dialysis populations. A synthesis of evidence was performed. The review of these studies provided evidence that was helpful in understanding how a nurse-led intervention can improve adherence in the dialysis population. The purpose of this project was to evaluate how a nurse-led intervention, based on an individual's health literacy level, affected dialysis compliance.

The objectives of the DNP project were as follows: 60% or greater of the 15 participants will maintain an interdialytic weight gain (IDWG) less than 4% of their estimated dry weight (EDW)during this project, 60% of the participants will complete every hemodialysis treatment and will not have missed or abbreviated hemodialysis treatments, all participants will be able to verbalize how missed or abbreviated treatments can affect their health, and there will be 10% or fewer hospitalizations or emergency room visits secondary to volume excess. Rescheduling a missed hemodialysis treatment within the same week as the missed treatment did not constitute as a missed treatment.

Definition of Terms

Hemodialysis treatment is a procedure used to remove excess fluid and filter toxins from the body in the absence of functioning kidneys. The pre-dialysis weight was the weight of the patient before dialysis treatment. The post-dialysis weight was the weight of the individual after

completing dialysis. The estimated dry weight was the estimated weight of the patient without excessive fluid. The IDWG was the difference between the pre-hemodialysis weight of the current treatment and post-hemodialysis weight of the last treatment. Large IDWG was considered a pre-hemodialysis weight gain greater than 4%. An abbreviated treatment, for this project, was defined as a reduction in hemodialysis duration of at least 10 minutes. A missed treatment was considered when a patient received less than three treatments a week.

Review of Evidence

The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Database of Systemic Review, and Pub Med were used to review the literature for this project CINAHL retrieved 1196 articles, Cochrane Database of Systemic Review retrieved 57 and PubMed retrieved 55. The following keywords were utilized: health literacy, ESRD, mortality, volume overload and compliance. The Internet search was minimized by defining the publication date, type of published paper, and language. In the final synthesis of evidence, a total of 15 articles were reviewed for application to the nurse-led intervention.

Educational Interventions

According to the United States Department of Health and Human Services, Health Resources and Services Administration, "Health literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent illness or treat illness" (2015). Research suggests that the mortality and morbidity risks increase with limited health literacy

(Campbell & Duddle, 2010). ESRD is the last stage of chronic kidney disease, at this point, dialysis (peritoneal or hemodialysis) or a kidney transplant is needed for symptomatic individuals to sustain life ("End Stage Renal Disease (ESRD): key facts and statistics," 2012). According to Clark, Farrington, and Chilcott (2014), non-adherence is common for the ESRD population due to the drastic lifestyle changes patients with ESRD are forced to endure, which can be very demanding and stressful.

Limited levels of health literacy are common in the population of patients receiving hemodialysis. Green and colleagues (2013) reported that limited health literacy among the population of patients receiving ESRD makes them more likely to miss treatment and be admitted to the hospital as a result of their kidney disease. Patients who were found to have limited health literacy were twice as likely to miss hemodialysis treatment versus those with adequate health literacy (Green et al., 2013).

Educational intervention including counseling improved dialysis attendance and shortened treatments. However, there were no significant changes in laboratory studies or interdialytic weight gain (Russell et al., 2011). Patients appear to be more compliant when they have a better understanding of their complications related to volume excess and missed treatments.

Cavanaugh and colleagues (2010) demonstrated a correlation between limited levels of health literacy and increased risk for death. Addressing health literacy by educating patients based on their health literacy levels may improve survival for this group of patients. Research

suggests that the majority of participants with low health literacy levels were male and non-white (Cavanaugh et al., 2010).

Owen and colleagues' (2009) findings stated a patient's literacy level could have an adverse impact on his or hers health, given low literacy levels affect compliance with medical treatment. Noncompliance with medical recommendations may be mostly due to patients not comprehending the educational materials they are provided when it is not targeted to the patient's health literacy level. Findings suggested that if appropriate literature is provided, patients will have a better understanding of their treatment and lifestyle regimen for their disease treatment (Owen et al., 2009).

The ESRD population is known to have a challenging lifestyle and non-adherence is very prevalent. Research supports the fact that this population often does not adhere to fluid compliance and treatment duration (Denhaerynck et al., 2007). Improvement in adherence in the dialysis population is possible with educational material targeted at the patient's health literacy level.

Conceptual Framework

The Health Belief Model was developed to explain and predict a patient's health behavior. The Health Belief Model will be used to guide this project. This model consists of six concepts which influence people's decisions regarding their action to prevent, screen for, or control illness (Glanz & Rimer, 2005). The six ideas are perceived seriousness, perceived susceptibility, perceived benefits, perceived barriers, cue to action, and self-efficacy.

Table 1. Health Belief Model Concepts with applications

Concept	Education According to Health Literacy Level
1. **Perceived Susceptibility**	Participants will believe they are at high risk for frequent hospitalizations and death when noncompliant with dialysis regimen.
2. **Perceived Severity**	Participants will believe that consequences related to noncompliance with dialysis regimen are significant enough to encourage them to be more compliant
3. **Perceived Benefits**	Participants will believe that complying with recommended dialysis regimen will decrease hospitalizations and complications related to volume excess.
4. **Perceived Barriers**	Participants will identify their personal barriers for not measuring fluid and/or for missing dialysis treatments or shortening treatments. Participants will explore ways to eradicate barriers.
5. **Cues to Action**	Participants will have reminder cues in the house (such as sticky notes with printed messages "measure all liquid", "I will never miss or shorten my hemodialysis treatments").
6. **Self-Efficacy**	Participants will be confident regarding restriction of fluid intake.

Implementation

Setting. The project was implemented at Fresenius Medical Center (FMC). FMC is a German health company which provides hemodialysis and peritoneal dialysis. FMC has a total of 3, 418 clinics worldwide and nine clinics located throughout Madison County, AL. The clinics are open Monday through Saturday. Three of the clinics provide nocturnal hemodialysis and are open seven days a week. Only five of the nine facilities were used for this project. All of the participants were enrolled in one of the following dialysis units: Chase Dialysis, Tranquility Dialysis, North Alabama Nephrology Center, West Madison Dialysis, or Odyssey Dialysis. All

of the data collection occurred at the dialysis centers. Permission was obtained to utilize FMC facilities for the DNP project, before initiation of study. Collaboration with the clinical mentor regarding this project occurred at Huntsville Renal Clinic.

Participants. The project included patients from Fresenius Medical Center (FMC). The inclusion criteria for the project were as follows: participants were enrolled in one of the five FMC hemodialysis units in Madison, AL; ages 18 years and older; diagnosis of ESRD and treated with hemodialysis for longer than 12 months; interdialytic weight gain (IDWG) greater than 4% for six months; and history of missed or abbreviated hemodialysis treatments the last six months. The inclusion criteria were obtained by completing a chart review, which included reviewing IDWG and attendance history. The exclusion criteria were as follows: participants 17 years old and younger, treated with hemodialysis less than 12 month period; diagnosis of acute renal failure; nursing home residents, wheelchair bound; and serum albumin less than 3.5g/dL. A convenience sample of 15 participants who meet inclusion criteria was invited to participate in the project

Protection of human subjects. The DNP project commenced after approval was received from the Institutional Review Board at The University of Alabama in Huntsville. Participation in the project was voluntary and the participants were free to withdraw from the project at any time. The participants were not exposed to physical or social risks during implementation of the DNP project. As a means to avoid unnecessary fatigue for the participants associated with completion of survey, questionnaires, and educational intervention, the participant completed all project

requirements during their regularly scheduled hemodialysis time. Survey responses were coded with a number for confidentiality and identification purposes to track objective data retrieved during the scholarly project, such as weight and treatment duration. All project data will remain in a locked cabinet when not utilized by the project author.

Timeline. Initially, patients with known history of volume excess were approached by the DNP Project investigator for possible participation in the DNP project. Patients who expressed interest in participation were given a HIPAA and consent form allowing the Project investigator to review their medical records (Appendix A). A demographic survey was completed (Appendix B). The participant's baseline health literacy was determined by the Rapid Estimate of Adult Literacy in Medicine revised (REALM-R). The REALM-R results provided the project author an assessment grade equivalent of the participants' comprehension (Appendix C). The participants received a pre-intervention questionnaire (Appendix D), which evaluated current level of understanding. Next, the participants received educational intervention targeted at their health literacy level. The educational interventions included oral information or hand-outs according to REALM-R score. Participants who scored six or less on the REALM-R received oral material for education. Participants who scored greater than six on the REALM-R received written materials for education. Topics of discussion were as follows: 1) Appropriate fluid intake for hemodialysis patients and helpful tips for limiting fluid intake and (Appendix E and 2) Complications related to volume overload (Appendix F). A post-intervention questionnaire (Appendix G) was administered to evaluate understanding post educational intervention.

The participants received education, ten minutes maximum, every two weeks for four weeks. Participants who receive hand-outs were asked to read the literature during designated intervention time. Participants who had a REALM-R score less than six received 5to10 minutes of oral education. Each participant was given a chance to ask questions regarding the content of educational literature. The objective data collected included pre-dialysis weight, post dialysis weights, attendance, and hemodialysis duration, and was collected at the end of the project.

Instruments

REALM-R. The Rapid Estimate of Adult Literary of Medicine-Revised (REALM-R), a pre-intervention questionnaire, post-intervention questionnaire and demographic survey were administered. The REALM-R, which assessed patients' ability to read common medical works, was distributed to each participant after signing the consent for the project. Arozullah and colleagues (2007) concluded that REALM-R is a valid tool for assessing health literacy in a diverse setting. In a study done by Bass, Wilson, and Griffith, the REALM-R was found to be reliable. The study consisted of 157 participants. These participants were given both the REALM-R and the Wide Range Achievement Test-Revised (WRAT-R). The Spearman rank correlation was 0.64, which supports a fairly strong relationship between REALM-R and WRAT-R with regards to identifying patients with low literacy (Bass, Wilson, & Griffith, 2003). There are also other researchers who support a positive correlation between REALM and other literacy tools (Alqudah, Johnson, Cowin & George, 2014). REALM-R is time efficient and only contains health-related words.

Investigator-designed instrument. A pre-intervention questionnaire was completed by the participants to evaluate their knowledge regarding adequate fluid intake, complications related to volume overload, and the risks associated with missed/abbreviated hemodialysis treatments. Educational interventions were administered two times during the four weeks of the project on topics related to fluid compliance and hemodialysis treatment compliance. Once the educational intervention was completed a 10-minute post-intervention test was administered to evaluate the participant's understanding. Total time to administer the surveys and educational information did not exceed 10 minutes. A demographic survey was completed to collect data regarding each participant (i.e., gender, race, age).

Data Analysis

Statistical Package for the Social Science (SPSS 24) was used to perform data entry and analysis (IBM, 2013). SPSS was used to analyze collected data from the project. The paired-samples t-test was used to determine if there was significant difference in the pre-intervention and post-intervention questionnaire and pre and post IDWG. Descriptive statistic was also used to analyze demographic data.

There were a total of 15 participants initially enrolled. The ages ranged from 33 years old to73 years old. The majority, 86.7%, of the participants had been on dialysis one to five years

and the remaining participants had been on hemodialysis six to ten years. One was removed from the study because of an unexpected hospitalization, due to volume excess. There were eight females and seven males. African Americans represented 53.3%, white (non-Hispanic) represented 40% and other represented 6.7% of the population of participants who participated in the project.

A paired-samples t-test was conducted to evaluate the difference in weight gain prior to intervention and after intervention. There was a statically significant decrease in weight gain from Time 1 (M=5.65, SD= 0.89) to Time 2 (M=4.26, SD=0.1.12), t (13) =6.776, p<0.0005 (two-tailed). The mean decrease in weight gain was 1.40 with 95% confidence interval ranging from 0.95 to 1.84. The eta square statistic (0.77) indicated a large effect size.

Another paired-samples T-test was conducted to evaluate the impact of nursing intervention on the subjects' knowledge as it relates to volume excess and missed/abbreviated hemodialysis treatments. There was not a significant increase in knowledge from pre-intervention questionnaire to post-intervention questionnaire. The probability value was 0.208, which was not a statically significant increase when comparing Time 1 (M=13.64, SD=2.341) to Time2 (M=14.71, SD=1.139), t (13) =1.325, p > 0.0005(two-tailed). The mean difference was -1.071with a 95% confidence interval ranging from -2.818 to 0.675. The eta squared statistic (0.12) indicated a moderate effect size.

Objectives were defined for the project. One included 60% or greater of the participants will curtail their IDWG to less than 4%. After the nurse-led intervention, 57% of the participants

decreased their IDWG to less than 4% of their IDWG. Another objective was 60% or greater of the participants will complete every treatment. Ninety-two percent of the participants completed all treatments, which consisted of three treatments a week. Hospitalization less than 10% was an objective defined for this project. There was one participant, 6.7% of the participants, hospitalized for volume excess.

Evaluation

Pre-hemodialysis weight, post-hemodialysis weight, interdialytic weight gain, and dialysis treatment duration were obtained at the beginning of the study and gathered throughout the study for four weeks. The participants were administered a pre-intervention questionnaire, a REALM-R tool, oral or handwritten literature regarding volume excess and missed treatments, and post-intervention questionnaire. The data for pre-hemodialysis and post-hemodialysis weights and interdialytic weight gain were reviewed and recorded for each hemodialysis, which was three times a week. Data regarding dialysis compliance and hospitalization admissions were recorded for each hemodialysis treatment. The project investigator was able to determine if nurse-led intervention based health literacy improved patients' compliance with hemodialysis treatments.

Application to Practice

Barriers and costs. It is important to anticipate barriers and then execute customized interventions to reduce barriers, for the change to be successful (Bostrom, Kajermo, Nordstrom, & Wallin, 2008). For example, assessing the health literacy of the dialysis patients will lead to

customized health education. Customized education allows for patients to receive instructions they can understand and implement, in order to improve their health. A limitation of this project was sample size. The size of the sample was not large enough to generalize to the hemodialysis population. This was mainly due to the inclusion criteria. There was minimal cost incurred for completion of the project. The only cost was for printing documents for the project.

Sustainability plan. To sustain this change within the organization, the REALM-R will have to be administered to all dialysis patients who have been on hemodialysis over 12 months to determine their health literacy level. Once this is established, appropriate education will be provided. The pre-intervention and post-intervention questionnaires will be utilized to ensure the education being delivered is appropriate.

Anticipated benefits

Implementation of this change in the organization will benefit the patients, insurance providers, and the organization. Most importantly, the patients' understanding of the disease process will improve, which could ameliorate their health status and decrease mortality. Insurance providers will benefit from improvement in dialysis adherence, reducing costly inpatient hospitalization/emergency room visits. The organization will benefit because it will increase revenue. Hospitals will also profit if patients are not readmitted within 30 days of discharge. According to the Affordable Care Act, section 1886(q), which was added to the Social Security Act, hospitals have the potential to lose up to 2% of their reimbursement for high 30-day readmissions. If hospitalizations are minimized, the physicians will be able to charge for

monthly in-center dialysis visits and receive the entire Dialysis Monthly Capitation Payment (CMS, 2016).

Conclusion

Health literacy assessment is important because it allows the provider to determine how individuals process and understand basic health information. Health literacy is essential when patients are required to participate in the management of their health care needs (Ishikawa & Yano, 2008). All providers should consider health literacy assessment of patients because this will improve the effectiveness of communication. Providing dialysis patients information based on their health literacy level can improve their outcomes with regards to compliance. In this small scholarly project we were able limit hospitalizations and increase compliance to treatment. Further research with a larger population is recommended to further explore the effect of education provided at the individual' health literacy level.

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Appendix A

HIPAA Privacy Authorization Form

**Authorization for Use or Disclosure of Protected Health Information

(Required by the Health Insurance Portability and Accountability Act, 45 C.F.R. Parts 160 and 164)**

1. Authorization

I authorize _____ (healthcare provider) to use and disclose the protected health information described below to _____ (individual seeking the information).

2. Effective Period

This authorization for release of information covers the period of healthcare from:

a. ☐ _____ to _____.

OR

b. ☐ all past, present, and future periods.

3. Extent of Authorization

a. ☐ I authorize the release of my complete health record (including records relating to mental healthcare, communicable diseases, HIV or AIDS, and treatment of alcohol or drug abuse).

OR

b. ☐ I authorize the release of my complete health record with the exception of the following information:

☐ Mental health records

☐ Communicable diseases (including HIV and AIDS)

☐ Alcohol/drug abuse treatment

☐ Other (please specify): _____

4. This medical information may be used by the person I authorize to receive this information for medical treatment or consultation, billing or claims payment, or other purposes as I may direct.

5. This authorization shall be in force and effect until _____ (date or event), at which time this authorization expires.

6. I understand that I have the right to revoke this authorization, in writing, at any time. I understand that a revocation is not effective to the extent that any person or entity has already acted in reliance on my authorization or if my authorization was obtained as a condition of obtaining insurance coverage and the insurer has a legal right to contest a claim.

7. I understand that my treatment, payment, enrollment, or eligibility for benefits will not be conditioned on whether I sign this authorization.

8. I understand that information used or disclosed pursuant to this authorization may be disclosed by the recipient and may no longer be protected by federal or state law.

_____

Signature of patient or personal representative

_____

Printed name of patient or personal representative and his or her relationship to patient

_____

Date

Appendix B

Consent Form

A Nurse-Led Educational Intervention Designed to Improve Compliance for Patients Receiving Hemodialysis

This is an invitation to participate in a research study about hemodialysis compliance. This study is designed to help us to better understand how educational intervention, targeted at an individual's health literacy level, effects hemodialysis compliance.

The primary investigator is Stephanie Mott from Huntsville, Alabama. She attends the University of Alabama in Huntsville as a Doctor of Nursing Practice student. She works as a nurse practitioner at Huntsville Renal Clinic. Huntsville Renal Clinic's Endstage Renal Disease patients receive hemodialysis at Fresenius Medical Centers. Fresenius has granted Stephanie Mott privileges to use their facility to provide care for Huntsville Renal Clinic patients.

Any time you have questions or concerns I may be contacted at snm0012@uah.edu or 256-434-1581.

PROCEDURE TO BE FOLLOWED IN THE STUDY: Once written consent is given, you will be asked to complete a screening that will tell how well you understand medical information. This screening will take less than five minutes to complete. Next you will be asked to take a pre-intervention questionnaire to determine your current knowledge regarding hemodialysis, which will take less than five minutes to complete. Education will be given based on your level of understanding for 3-5 minutes. After completing the education regarding hemodialysis, a post-intervention questionnaire will be given to see if your knowledge regarding hemodialysis has increased. This final test will take less than five minutes to complete.

The length of the project will be four weeks.

DISCOMFORTS AND RISKS FROM PARTICIPATING IN THIS STUDY: There are not potential physical or social risks related to the participation in this project. All interaction will take place during your regularly scheduled hemodialysis visits. Project documents completed will be coded with a number and will remain locked in a file cabinet when not being utilized by the project investigator for data analysis, for which the investigator has the sole key. Your data will be placed into a password-protected file for the purpose of statistical analysis, passwords will only be known to the project investigator. Paper documents will be destroyed once the electronic file has been created. There are no economic or legal risks to the participants within the course of this project.

EXPECTED BENEFITS: The potential benefits of this project are as follows: 1) Improve patients' knowledge on critical management parameters of lifelong chronic disease; 2) improve adherence to patients' self-management of volume consumption; 3) Reduction in hospitalizations admissions and emergency department visits related to volume excess and missed treatments

CONFIDENTIALITY OF RESULTS: Numbers will be used to record your data and these numbers will be made available only to the project investigator, thereby ensuring strict confidentiality. This consent form will be retained for 3 years, per federal regulations governing human subject research.
The data from your session will only be released to those individuals who are directly involved in the research and only using your participant number.

FREEDOM TO WITHDRAW: You are free to withdraw from the study at any time. This study is completely voluntarily. You will not be penalized because of withdrawal in any form. Investigators reserve the right to remove any participant from the session

without regard to the participant's consent. Your decision to participate or not participate in this research study will have no effect on the care or services you receive at Huntsville Renal Clinic or Fresenius Medical Center.

CONTACT INFORMATION: If any questions should arise about this study or your rights as a participant, you may contact the Principal Investigator at any point in the research process. You may contact Stephanie N. Mott in Huntsville, Alabama at snm0012@uah.edu or 256-434-1581. If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the Office of the IRB (IRB) at 256.824.6101 or email Dr. William Wilkerson at irb.@uah.edu.

If you agree to participate in our research please sign and date below.

This study was approved by the Institutional Review Board at UAH and will expire in one year from <date of IRB approval>.

_____ _____

Name (Please Print) Signature Date

_____

Parent/Guardian Signature (if younger than 18)

Appendix C

Identification Number_____

Demographics Questionnaire

Today's date (dd/mm/yyyy) _ _ /_ _ /_ _ _ _

1) Name:_____

2) Telephone number :_____

3) City you live in:_____

4) Gender
a. Female
b. Male

5) What is your race/ethnicity? (Circle all that apply)
a. African American/Black
b. White, non-Hispanic
c. Hispanic
d. Asian
e. American Indian or Alaska Native
f. Native Hawaiian or other Pacific Islander
g. Other_____

6) What is your marital status?
a. Married

b. Divorced
c. Widowed
d. Separated
e. Never married

7) Age
a. 20-29 years old
b. 30-39 years old
c. 40-49 years old
d. 50-59 years old
e. 60-69 years old
f. 70-79 years old

Identification Number_____

8) How long have you been on hemodialysis?
a. 1-5 years
b. 6-10 years
c. 11-15 years
d. 16-20 years

9) Highest level of education?
a. Less than high school degree
b. High school degree/GED
c. Some college, but no degree
d. Associate Degree_____
e. Bachelor Degree_____
f. Graduate Degree_____

Appendix D

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE, REVISED (REALM-R)

The REALM-R is a word recognition test consisting of 11 items used to identify people at risk for poor literacy skills (Bass et al, 2003). Words that appear in this test are:

Fat	Osteoporosis	Anemia	Colitis
Flu	Allergic	Fatigue	Constipation
Pill	Jaundice	Directed	

Fat, Flu, and Pill are not scored and are positioned at the beginning of the REALM-R to decrease test anxiety and enhance confidence.

SPECIAL CONSIDERATIONS WHEN USING THE REALM-R

1. **Examiner Sensitivity**

   Many adults with low literacy skills will attempt to hide their deficiency. Ensure that you approach each person with respect and compassion. You may need to provide encouragement and reassurance. Many people with low literacy feel ashamed. Be sensitive.

2. **Visual Acuity**

   If the person wears glasses, ask them to wear the glasses for the test. The word list should be set in 18-point font.

3. **Pronunciation**

   Dictionary pronunciation is the scoring standard.

4. **Dialect, Accent, or Articulation Problems**

   Count a word as correct if it is pronounced correctly and no additions or deletions have been made to the beginning or ending of the word. For example, a person who says "jaundiced" would not receive credit for the word "jaundice"; "directs" would not receive credit for the word "directed". Words pronounced with a dialect or accent should be counted as correct, provided there are no additions or deletions to the word. Particular attention should be paid to persons who use English as a second language.

5. **Limitations of the REALM-R**

   The REALM-R can only be used for persons who read English; it has not been validated in other languages.

Source: adultmeducation.com

ADMINISTRATION

1. Print the list in 18-point font or greater.

2. Introduce the REALM-R to the person. The words "read" and "test" should be avoided when introducing and administering the REALM-R. The following statement can be used to introduce the REALM-R:

> "Sometimes in the health care system, medical words are used that many people are not familiar with. I would like to get an idea of what medical words you are familiar with."

3. Give the person the list of the REALM-R words. Point to the first word and ask the person read the 11 words out loud. Be sensitive to dialect, accent, and articulation problems.

4. If the person takes more than five seconds on a word, they should be encouraged to move on to the next word (e.g., say "Let's try the next word."). If the person begins to miss every word or appears to be struggling or frustrated, tell them, "Just look down the list and say the words you know."

SCORING

Use the REALM-R Examiner Record to record the outcome of the test. The words Fat Flu and Pill are not scored. Count as an error any word that is not attempted or is mispronounced. Place a check mark ("√") next to each word the person pronounces correctly, and an "X" next to each work the person does not attempt or mispronounces. Those with a score of 6 or less should be considered to be at risk for poor health literacy.

Source: [illegible]

Appendix E

Pre-intervention Questionnaire

1) Are you required to limit the amount of liquid you drink in 24-hours?
a. Yes
b. No

2) Can drinking too much fluid in 24-hours increase your risk for hospitalization or emergency room visits?
a. Yes
b. No

3) Which of the following can be caused by too much fluid intake? (Circle all that apply)
a. Swelling
b. Increased blood pressure
c. Shortness of breath
d. Make you feel better
e. None of the above

4) Does high sodium diet (greater than 2000mg/24 hours) affect your volume status?
a. Yes
b. No

5) How much fluid should dialysis patients consume in 24 hours?
a. As much they want
b. Over 2000ml (2L)/24 hours
c. 1500ml (1.5L)/24 hours
d. 600ml/24 hours

6) Can limiting your sodium intake help you manage your fluid intake?
a. Yes
b. No

7) Which of the following has to be included in your fluid count? (Circle all that apply)
a. Water
b. Juice
c. Ice chips
d. Ice cream
e. Grapes
f. Jell-O
g. Chicken sandwich
h. Strawberries
i. All of the above

8) Can excessive fluid intake affect the heart?
a. Yes
b. No

9) Can excessive fluid intake cause fast pulse (heart rate), weaken the heart muscles, and cause enlarged heart (big heart)?
a. Yes
b. No

10) What are consequences of excessive fluid gain?
a. Sudden decrease in blood pressure
b. Nausea
c. Dry mouth
d. Cramping
e. Excessive thirst
f. Fatigue (tired)
g. Dizzy
h. None of the above

i. Confusion
j. All of the above

11) Can keep a daily log of fluid intake help manage fluid intake and keep fluid intake less than 1500ml/day?
a. Yes
b. No
12) Should ice be counted in your daily fluid intake
a. Yes
b. No

13) Can missed hemodialysis treatments shorten your life span?
a. Yes
b. No

14) Can shortening your treatment by as little as 10 minutes affect your life?
a. Yes
b. No

15) Missed treatments can cause excessive fluid to accumulate?
a. Yes
b. No

16) Do you have any question(s) related to fluid intake?
a. No
b. Yes, if yes please list your question(s) below

Appendix F

WHAT IS APPROPRIATE FLUID INTAKE FOR HEMODIALYSIS PATIENTS?

- 1500ml/1.5L/50 ounce in 24 hours is acceptable for dialysis patients. This amount can vary depending upon urine output amount. Patients who still produce urine are able to deviate slightly from this recommendation; however, as the urine output decreases you will have to return daily fluid intake to 1.5L.
- 1L of fluid is equal to 1kg
- If you drink 1.5L of fluid in 24 hours you will have acceptable gain between treatments

UNDERSTANDING WHAT COUNTS AS FLUID

- Remember anything that turns to liquid at room temperature has to be counted as fluid intake
- Water for drinking and taking medications
- Ice cubes
- Coffee/tea
- Soda, alcohol, drinks, lemonade
- Milk, cream, liquid creamer, milk shakes
- Juices (fruit and vegetables)
- Soups and broths
- Ice cream, sherbet, sorbet, and popsicles
- Jell-0
- Grapes

HELPFUL TIPS FOR LIMITING FLUID INTAKE

- Complete entire treatment, to ensure you reach your dry weight at the end of treatment
- Use smaller cup(4ounces) for drinking
- Try freezing fruit (i.e., grapes, blueberries) for snacks
- Chew gum and eat hard candy to help keep mouth moist
- Maintain good blood glucose control. Elevated glucose increases thirst, which increases fluid intake
- Limit sodium intake to 1500mg/day. Sodium causes fluid retention, which is why limiting sodium is important
- Avoid processed foods (i.e. lunch meat, canned foods, frozen dinners)
- Add lemon juice to water to help quench thirst
- Dilute mouthwash with water (½ and ½), label, and place in refrigerator. Use to rinse mouth when thirsty. DO NOT DRINK
- Eat popsicles when thirsty. Only 2 ounces of fluid
- Use ice cubes to quench thirst. 1 cup of ice= ½ of liquid'
- Record all fluid intake

Appendix G

Complications Related to Volume Overload

- Weaken Heart: This stops the heart from pumping as fast as it needs to circulate the blood appropriately. Also, congestive heart failure can lead to a heart attack.
- Swollen feet/hands: This is due to excessive fluid pooling under the skin
- Elevated blood pressure: Increase in blood pressure due to the extra fluid in the blood vessels
- Difficulty breathing (can occur at rest or with activities): This is due to extra fluid collection in the lung space and making it hard for the lungs to oxygenate.
- Chronic cough: This is also due to fluid collecting in the lungs
- Cramps: This is due to removal of large amounts of fluids during treatment as a result of large gain between treatment
- Low blood pressure during treatment: Decrease in blood pressure can occur if large amount of fluid is removed over a short period of time
- Abdominal fluid: Fluid can collect in the abdomen. This occurs with volume excess. This fluid is not removable through hemodialysis. This will require a different procedure, which requires insertion of a needle into the space and the fluid removed.
- Hospitalization due to respiratory complications

Appendix H

Post-intervention Questionnaire

17) Are you required to limit the amount of liquid you drink in 24-hours?
c. Yes
d. No

18) Can drinking too much fluid in 24-hours increase your risk for hospitalization or emergency room visits?
c. Yes
d. No

19) Which of the following can be caused by too much fluid intake? (Circle all that apply)
f. Swelling
g. Increased blood pressure
h. Shortness of breath
i. Make you feel better
j. None of the above

20) Does high sodium diet (greater than 2000mg/24 hours) affect your volume status?
c. Yes
d. No

21) How much fluid should dialysis patients consume in 24 hours?
e. As much they want
f. Over 2000ml (2L)/24 hours
g. 1500ml (1.5L)/24 hours
h. 600ml/24 hours

22) Can limiting your sodium intake help you manage your fluid intake?
c. Yes

d. No

23) Which of the following has to be included in your fluid count? (Circle all that apply)
j. Water
k. Juice
l. Ice chips
m. Ice cream
n. Grapes
o. Jell-O
p. Chicken sandwich
q. Strawberries
r. All of the above

24) Can excessive fluid intake affect the heart?
c. Yes
d. No

25) Can excessive fluid intake cause fast pulse (heart rate), weaken the heart muscles, and cause enlarged heart (big heart)?
c. Yes
d. No

26) What are consequences of excessive fluid gain?
k. Sudden decrease in blood pressure
l. Nausea
m. Dry mouth
n. Cramping
o. Excessive thirst
p. Fatigue (tired)
q. Dizzy
r. None of the above
s. Confusion
t. All of the above

27) Can keep a daily log of fluid intake help manage fluid intake and keep fluid intake less than 1500ml/day?

c. Yes
d. No

28) Should ice be counted in your daily fluid intake

c. Yes
d. No

29) Can missed hemodialysis treatments shorten your life span?

c. Yes
d. No

30) Can shortening your treatment by as little as 10 minutes affect your life?

c. Yes
d. No

31) Missed treatments can cause excessive fluid to accumulate?

c. Yes
d. No

32) Do you have any question(s) related to fluid intake?

c. No
d. Yes, if yes please list your question(s) below