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The effects of health literacy on treatment adherence and health optimism in chronic kidney disease patients

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Kidney Disease Patients

By

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Abstract

Health literacy is a very critical aspect of a patient's recovery, and low levels of it have been correlated to a large range of negative health outcomes. Health literacy's effects on treatment adherence and health optimism was examined in a sample of 32 Chronic Kidney Disease (CKD) patients who were recruited from a transplant center in the southeastern section of the United States. Participants had a mean age of 47.55, with 45.2% (n=14) of the participants being female and 54.8% (n=17) being Caucasian. The participants completed a survey, which incorporated the tools of Health Literacy Questionnaire, Life Orientation Tool, and the PlAnk 4 scale. The study found that (1) Health literacy was positively correlated with Health Optimism and (2) Health Literacy had a positively correlated with Treatment Adherence, supporting both of the study's hypotheses. This study's findings highlight the importance of health literacy in CKD and its association with health outcomes.

Keywords: Chronic Kidney Disease, End Stage Renal Disease, Health Literacy, Health Optimism, Treatment Adherence

The Effects of Health Literacy on Treatment Adherence and Health Optimism

The main function of the human kidney is to remove wastes and fluids from throughout the body through the production and secretion of urine. Kidneys filter out the toxins to maintain a stable healthy balance of chemicals in the body (NIDDK, 2018). However, when an individual's kidney is unable to function correctly, these individuals have the potential to develop chronic kidney disease (CKD), which creates great complications for their health and overall wellbeing (NIDDK, 2018). From 1988-1994, the prevalence of chronic kidney disease was only 10%, and by 1999-2004 it quickly rose to 13.1% (Coresh, 2007). Today, unfortunately, CKD currently affects about 37 million American adults, which is around 14.8% of the adult population, and costs the United States about $114 billion in Medicare. One in every seven American adults is living with CKD (USRDS, 2016). This demonstrates the rapid increase in prevalence rates of (CKD) over the past couple decades.

CKD develops over time in the body. This progression is divided into 5 stages of disease development. If not found early on, CKD gradually begins to develop in the body, and the kidney condition continue to worsen (Hogg et al., 2003). Patients experience initial symptoms and are said to have CDK when they have limited kidney function for at least 3 months (Hogg et al, 2003). Symptoms of CKD can range from extreme fatigue to poor appetite to frequent urination. However, many people do not experience extreme symptoms, making it very important that individuals to get tested if they could be at risk (CDC, 2017). It is estimated that about 9 out of every 10 adults that have CKD are unaware of their diagnosis in the early stages, and thus this allows for them to become very sick (CDC, 2019). Thus, CKD can easily persist in the human body.

When the disease has developed to stage 3, only about 10% of patients are aware, due to the lack of testing and patient awareness (Plantinga, et al., 2008). Moreover, by the time the disease progresses to stage 4, only 57% of individuals are aware of the disease. At this point the disease is considered to be in advanced development (USRDS, 2018). However, at the very advanced last stage, end stage renal disease (ESRD), kidneys have almost lost their complete function. They are operating at 10% or less of their potential (USRDS, 2018). During this final phase of ESRD, patients must undergo an extensive and time-consuming process called dialysis, until they can hopefully receive a kidney transplant. They most likely will not be able to survive without treatment of a new functioning kidney (USRDS, 2018).

Treatments for ESRD

Dialysis is a form of treatment that removes certain wastes and fluids from the body, to help maintain the normal homeostasis, or equilibrium of chemical levels, which is essentially the same process that healthy kidneys would perform. In other words, dialysis is a way to help compensate for the kidney lost functions, through extensive medical treatment (CDC, 2018). Currently, more than 660,000 Americans are getting help with their ESRD, and 468,000 are on dialysis (NKF, 2016). In 2004, the survival rate for these individuals was only about 80%, and these services cost the United States about $23 billion dollars a year (Go, et al., 2004). In 2013, the ESRD population was only 1% of Medicare patients, but together, they spent 7% of the Medicare budget, which is a very significant proportion (The Kidney Project, 2013). Currently, of the 124, 692 individuals waiting for an organ donation, 103,126 are kidney patients, and this number

continues to rise (OPTN, 2019). Kidney patients stand out among organ patients due to their high demand and limited supply.

Usually, patients get dialysis treatment three days a week for about four hours a session when they have been diagnosed with ESRD (Nordqvist, 2018). Most patients have lost about 85-90% of their kidney function when they start dialysis therapy. This means they are most likely in the fifth and final stage of CKD, with dialysis compensating for the individual's failing kidney (Nordqvist, 2018). There are two types of dialysis that patients usually undergo. In the first form of dialysis, *hemodialysis*, the patient's blood is circulated outside of their body through a catheter, into a machine, that filters out the toxins and replenishes the patient with new, clean blood from another catheter. This process usually takes place at the transplant center and occurs about 3-4 days a week for 3-4 hours a session (Nordqvist, 2018). In the second form, *peritoneal dialysis*, a sterile solution enters through the membrane of the patient's abdominal cavity, and helps to absorb toxins near the intestines (Nordqvist, 2018). To complete this type of dialysis, it takes about 30-60 minutes to get the solution into the human body, and then the CKD patient must change the solution about four times a day, as it only works in the stomach for about 4-6 hours (NIDDK, 2018). Both processes are extremely time consuming and alter the patient's life to a great degree.

Research has discovered that there are great divisions and limitations in access to kidney transplant and treatment in regards to ESRD patient's race. Clark, Hicks, Keogh, Epstein and Ayanian, (2008) discussed how African American patients are much less likely than their White counterparts to receive transplants recommendations from their health care providers. This then causes them to have a lower likelihood of being placed

on a kidney transplant waiting list, limiting their chances of getting a transplant (Clark et al. 2008). On a broader racial scale, in general, US minorities overall have been found to be 2-4 times more likely to develop ESRD than their White counterparts (Churak, 2005). However, studies found that in 2019, 54.8% of total transplants were given to White patients, while only 21.3 % were given to African Americans and 16.7% to Hispanics (OPTN, 2019). These proportions do not correlate to the overall demand.

Aside from race, a patient's social interactions and support groups also impacts their recovery and transplant success. More specifically, levels of social support have been correlated to different health outcomes. Thus, low social and emotional support is directly correlated to a decreased likelihood of the patients completing their pre-transplant evaluations. This correlation continues to slow down the patient's chance for a recovery (Clark et al, 2018). Clark et al. (2018) found this relationship to be true in their study. These researchers discovered that many of these patients tend to find comfort with and connections to their dialysis centers and the individuals there. Due to this level of social support, the patient's do not want to leave the centers because they lack the same support in their personal lives, and thus in some cases they do not follow all the necessary measures to get a transplant and be taken off dialysis (Clark et al., 2018).

Health Literacy

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Chisholm, Fair & Spivey, 2007, p. 800). Research has claimed that health literacy is one of the most essential components of a patient's ability

to adhere to their treatment schedules and disease obstacles in all fields of illness and disease (Martin, Williams, Haskard, & Dimatteo, 2005). It is estimated that in the United States, over 90 million patients do not have the proper health literacy skills to correctly and appropriately take care of their medical needs (Millers, 2016). Health literacy in patients undergoing chronic hemodialysis treatment for their CKD has been found to be directly associated to death rates. The lower patient's health literacy, the less chance they have of survival (Cavanaugh, et al., 2010). Specifically, in elder patients, ages 65 and up, past studies have found a correlation between patient's level of health literacy and their mortality rates (Baker, Wolf, Feinglass & Thompson, 2008). Specifically, in CKD patients, research has discovered a moderate relationship between the increased risk of death and low health literacy (Cavanaugh, et al., 2010). This means that individuals are more susceptible to death if they have a lower understanding of their CKD.

Chisholm et al, (2007) found a negative effect of low health literacy on their sample's health. What they observed in their study of 36 kidney transplant patients was that lower levels of literacy about their medical care led to increased hospitalization, higher medical costs and thus an overall poorer health status (Chisholm, 2007). Due to this, health literacy has further been found to impact patients' physical wellbeing, emotional distress, and social support (Kalichman, 2008). In other words, what these researchers found is that health literacy is a key factor in CKD patients' health, and individuals who have higher levels of kidney literacy, tend to have better overall health outcomes (Chisholm, et al.,2007).

Other studies have also looked at whether health literacy has any effect on patient's access to transplant care and treatment. Grubbs, Gregorich, Perez-Stable & Hsu

(2009) looked at 62 participants receiving maintenance hemodialysis. They learned that health literacy had a direct effect on many components on kidney transplant, such as lowering your rate of referral to a transplant evaluation and decreasing your likelihood of completing the necessary steps in the process towards a kidney transplant (Grubbs, et al, 2009). The patients who were less educated about their ESRD, experienced excessive barriers. Many times these patients did not understand the steps they needed to take to be placed on the waiting list, and because of this experienced much longer wait times, and a decreased likelihood of receiving a kidney (Grubbs, et. al, 2009). Similarly, patients who have lower education levels and a less comprehensive understanding of their diagnosis, were found to have more health problems (Cavanaugh, et al, 2010). Due to the nature of ESRD, patients are required to complete multiple steps before their transplantation and thus health literacy is very important because in order for these steps to successfully be completed, patients must understand their disease, and what they need to do to improve their health.

Treatment Adherence

However, more specifically, the effects of health literacy have been studied in relation to medical treatment adherence in a number of patient samples. Researchers have found that when patients are not adequately informed and do not have a clear understanding of their disease, or have low health literacy, they are at a greater risk of non-adherence to their medicine (Miller, 2016). The effects of health literacy have been found in a wide range of patients. One study, looking at a sample population of HIV patients, found that 64% of patients who were diagnosed with HIV and had a ninth-grade

level of reading or greater took 95% of their ARV medication while the patients with less

than a ninth grade reading only took about 40% of their required medicine. That is a

significant difference, that showed just how powerful the effects of literacy, both

medically and educationally, can be on patient's medical adherence (Kalichman, et. al,

2008).

More specifically in kidney patients, researchers have found that health literacy

can be an overall barrier in accessing, understanding and using health information and

services about the transplant process, which thus concludes in many adverse and negative

side effects for the patient (Chisholm, 2007). Low health literacy studied in a group of

ESRD patients with diabetes, was further associated to non-treatment adherence due to

the decreased ability to conduct medical self-management, which caused these patients to

have poorer prognosis. When patients did not understand their ESRD, they lost control

over their care, and in conclusion could not correctly follow their medical regiment (Lai,

2013). Through these findings, it is clear that CKD patients must have the resources to

learn about their kidney disease and transplantation so they have an easier time during

their medical experience and have a better chance of a healthy life.

A research review looked at 1405 ESRD patients observed across 82 different

studies, and learned that 22.7% of these individuals in the sample had a poor prevalence

of health literacy (Fraser, Roderick, Casey, Tall, Yuen & Nutbeam, 2013). A low level of

patient health literacy caused them to become more vulnerable to health problems, and

unpleasant physical and emotional side effects thus impeding on the patient's treatment

adherence (Fraser, et al., 2013).

Looking more at the specific effects of low levels of treatment adherence, a study examined ESRD patients with allograft loss. Patients must return to dialysis when they experience allograft loss after transplantation, which greatly increases they chance of mortality (Nankivell & Kuypers, 2011). Allograft failure has been correlated to treatment adherence given that rejection likely occurred because the patients were not taking their medications appropriately. It was learned that about 36% of patients with allograft loss, usually develop this problem because of non-adherence to their medicine. This study exhibited the extreme harm that non-adherence can have on a patient's health (Prendergast & Gaston, 2010). Thus, it is evident that low treatment adherence really interferes with patient's recovery and health in a negative way.

Dosing frequency, or the number of drugs and medicine a patient has to take, has been found to negatively impact ESRD patient's medical adherence. Studies have found that dosing frequency is directly correlated to medical non-adherence. Due to the high doses of drugs given to ESRD patients, there is an increased likely for confusion with patient's medical treatment schedule and thus higher likelihood that they may mess up their treatment process (Prendergast, 2010). Thus, ESRD patients are even more susceptible to this negative effect on their health, as their sickness currently demands a lot of treatment. Another aspect of ESRD that has the potential to be affected by health literacy and patient's outlook on their recovery is their level of health optimism about their sickness and recovery.

Health Optimism

Optimism in this study is defined as "the inclination to hope" and "the tendency to believe that we live in *the best of all possible worlds*" (Conversano, Rotondo, Lensi, Della Vista, Arpone & Reda, 2010, p. 25). However, to incorporate the aspect of health, viewing optimism in regards to the attitudes a patient has about their self rated care. Health optimists are many times considered the opposites of poor- health realists (Van Doorn, 1999, p. 440). Essentially help optimism is how you view, understand and accept your medical diagnosis, treatment and recovery. Not many researchers have studied the impact of health literacy on kidney patient's perspective of their disease and their overall health optimism for their recovery. However, other populations of patients have been examined. For example, in one study looking at an outpatient clinic of cancer patients, it was found that increased optimism in this sample was connected to less anxious and depressive symptoms and an overall improved quality of life (Applebaum, Stein, Lord-Bessen, Pessin, Rosenfield, Breitbart, 2014). Optimism could potentially have the ability then to provide patient with strength and hope about their disease. Essentially if patients have a strong positive outlook on their recovery, this could greatly help their overall medical experience (Applebaum et al., 2014).

Only a few studies have looked at the effects that optimism on coping strategies and recovery in kidney patients. Costa-Requena, Cantarell- Aixendri, Parramon- Puig & Seron- Micas (2014) examined the effects of dispositional optimism in patients who had received a kidney transplant, and more specifically the relationship this has with the patient's coping styles. Dispositional optimism in this study was defined as "a personal resource that determines the coping style and adaptive response to chronic disease"

(Costa- Requena et al., 2014, p. 605). The researchers studied 66 patients who had just recently, within the month, undergone kidney transplantation. What they found was that dispositional optimism had a positive and direct relationship with coping strategy, which means that those who had more active coping strategies were found to have higher scores of dispositional optimism (Costa Requena et al., 2014). Thus, dispositional optimism, or higher levels of health optimism were directly found to increase patients' quality of life.

Over 84 studies have found that optimism is a significant predictor of physical health, and that optimism does indeed have a very positive role on individual's physical well-being (Rasmussen et al. 2010). Christensen et al. (1991) found this to be true in ESRD patients. ESRD patients who held a belief that their transplant was not going to be rejected, and that they had control over the experience, were more optimistic in regards to their treatment and mental health (Christen et al., 1991). In other words, patients who understood, or had higher health literacy, were thus more likely to find hope in a recovery, and formulate higher levels of optimism (Christensen et al., 1991). In addition, when patients had more control over their disease, they were associated with less depressive symptoms (Christensen et al., 1991).

The current study focuses specifically on the impact that health literacy has on a patient's wellbeing, and whether there is a correlation between how much a patient knows about their ESRD and the positive health outcomes. Many studies in the past have found that health literacy can greatly impact the medical experience for CKD patients. Researchers have found that in particular, health literacy can significantly impact a patient's health optimism and treatment adherence. More specifically, the research question is whether there is a correlative relationship between health literacy and ESRD

patient's treatment adherence as well as a correlative relationship between health literacy and health optimism. Not many studies in the past have looked at the direct correlative effects of health literacy on both of these variables, without outlying variables. This study was guided by the following hypothesizes. First, there would be a direct and positive correlation between health literacy and treatment adherence. The second hypothesis is there will be a direct and positive correlation between health literacy and health optimism. .

Methods

Participants

Participants in this study were self-identify adult, ESRD patients that were recruited from a pool of patients who were currently on the waitlist, taken off the waitlist or transplanted patients found at a transplant center. Many of these patients were recruited from a transplant center in the Southeastern region of the US. However, a few were found through a social media posting on Facebook and LinkedIn, as well as word of mouth from other participants. In order to qualify for this study, patients had to be over the age of 18, be able to read English and had to have experienced barriers or problems during their steps to getting a kidney transplant. Since, this study is part of a larger study, it is important to note the sample only consisted of CKD who experienced barriers. In order to begin the survey, patients had to click "yes" to the question asking if they underwent barrier, and then had to explain these. Only after this, could the participants have access to the study's full survey. The current study recruited 32 patients of which 30 completed all parts of the study. There was a mean age of 47.55 (*SD,* 13.7), with the

majority of participants 51.6% being male (*n*=16), 54.8% being Caucasian (*n*=17),

66.7% being unemployed (*n*=20) (See Table 1).

Procedure

All participants were recruited to this study through an invitation letter sent from

the principal investigator's (PI) research team sent via mail. Each letter was followed up

by a phone call, in which members of the research team asked a series of questions to

confirm the participant's eligibility, and then offered a verbal invitation to participate.

The research team called each patient a maximum of 5 times, before eliminating him or

her from the list of potential participants. Also, flyers were placed in dialysis centers and

local businesses. Lastly, the survey was posted on social media, through Facebook and

LinkedIn, where CKD patients could click the survey link and complete the study at their

own convenience. All participants were also encouraged to share this information to

anyone they know who might qualify for this study. Participants then had the option to

take the survey either in person at their transplant center, a study's location (a private

university), online or via mail with return postage. Due to the fact that the sample of

participants are part an extremely sensitive and vulnerable population, proper, respectful

and transparent protocol was used throughout the study.

This research study is part of a larger study that sought to develop a measure of

barriers in access to transplantation. Due to this, three surveys were incorporated into the

larger study, to formulate the results of this research project. Recruited participants had

the option to pick between the two separate surveys. However, all the participants

observed in this study, used survey option two. The second survey option, which took

approximately 25-30 minutes to complete, added in the necessary components for this specific study and included the subscales for measuring treatment adherence and health optimism. The participants who completed survey 2 were given $15 for their time and commitment.

Study's Measures

The current study gathered demographic information as well as a series of survey response, to collect data from the participants. Through a series of introductory questions, participants were asked to state their age, gender, race, education level, employment status, and occupation, amongst other general variables to better understand the sample's descriptive statistics (See table 1). Upon completion, the participants then began to work on the survey section of the study.

Participants were asked to complete a survey looking at many aspects of their health. The main three components observed in this study were treatment adherence, health optimism, and health literacy. However, apart from the three main variables, health literacy, health optimism, and treatment adherence, participants were asked to complete some other questionnaires. At the start of the study, participants were asked to answer two questionnaires focusing on their barriers in access to transplant. To measure this, participants first completed the Barriers in Access to Transplantation Scale, which is a culturally sensitive psychometrically sound measure to better understand which patients are at the greatest risk of experiencing barriers in their attempt to get a kidney transplant. Participants were asked to reflect on their own transplant experience through a series of 59different question rated on a 5-point scale (Nonterah, n. d.). The next measure was the

Barriers to Access to Care Evaluation (BACEv3) which is a self- completed 4-stage

psychometric measure accessing the barriers of dealing with, and seeking out mental

health services and care. The BACEv3, which is the specific part used for this survey,

consists of 30 separate items, including 12 stigma related questions (Clement &

Thornicroft, 2011).

Another aspect of the study that was used to measure kidney specific health

literacy was the Rapid Estimate of Adult Literacy in Medicine Transplantation REALM-

T survey. The REALM- T is a word recognition test used to provide clinicians with an

assessment of patient health literacy (Gordon & Wolf, 2009). The modified version of

this study, which focuses on transplantation measures patients' knowledge of kidney

transplantation terms, was used in this survey (Kazley et al., 2015).

Health Literacy. The Health Literacy Questionnaire (HLQ) is a multi-

dimensional tool that consists of 44 questions, with 8 subscales designed to encapsulate

people's experience of trying to understand, access and engage with health information

and health services (Osborne et al., 2013). The HLQ was developed to help diagnose and

improve health literacy needs across the medical field, to better understand the wide

range of perspectives in the healthcare field (Osborne et al., 2013). The HLQ has two

sections of the study that are averaged together to create a score for each participant on

their average of the full survey. Part one, asked the participant's to rate how strongly they

agreed or disagreed with a number of statements using a Likert scale (4 = strongly agree,

3= agree, 2 = disagree, 1 = strongly disagree). Part two asks the participants to rate how

strongly they agree or disagree to a number of statements using a 1-5 scale (5=always

agree, 4= usually agree, 3= sometimes difficult, 2= usually difficult, 1= cannot do or always difficult). Sample questions include "I feel I have good information about my health" and "I have all the information I need to look after my health." This scale was originally has been used in a research and found to have a Cronbach's *a* that ranged from 0.91 to 0.94 (Ware, Kosinko & Keller, 1995). This current study had a Cronbach's *a* of .981 for the 44 items scored. To get the participants score on health literacy, an average was taken from their responses to the 44 questions.

Health Optimism. To measure health optimism the Life Orientation Test was used (CITE). This instrument has been used for research on the measurement of both optimism and pessimism. It also looks at other factors of mental health, more specifically the concept of depressing and self-esteem (Scheier, et al, 1994). Participants are asked to rate a list of 10 items on a 5-point scale (5= I agree a lot, 4= I agree a little, 3= I neither agree or disagree, 2= I disagree a little, 1= I disagree a lot). Sample questions include "In uncertain times, I usually expect the best" and "I rarely count on good things happening to me." To score this scale, 3 of the questions must be reverse coded, and the 4 filler items are removed. From there, the participants receive their score from a sum of the remaining, 6 questions. Scheier, et al. (1994) reported a Cronbach's *a* of .82. The current study found a Cronbach's *a* of .821 for the 10 items on the health optimism scale.

Treatment Adherence. To measure treatment adherence, The Morisky Scale (PlAnk 4 Tool) by Morisky, Green & Levine, 1986 was used. The PlAnk 4 tool is a self-reported scale that observes the medication taking behaviors of patients, to better understand their adherence to their medicine (Morisky, 1986). This section asked participants to answer a series of 4 questions where they could state either "yes" or "no"

in regards to if they forget to take their medicine, or if they ever purposely stop due to their feelings towards their sickness. Sample questions include "Do you ever forget to take your medicine" and "when you feel better, do you sometimes stop taking your medicine." The Morisky Scale was the tool used to measure treatment adherence for this specific research study. Morisky (1986) reported an internal consistency of Cronbach's a 0.61. In this current study the Cronbach's *a* was 0.786.

Results

Data Analytic Plan

After the completion of the cross- sectional survey results, the data collected was further analyzed. The information was coded into IBM Statistical Package for the Social Science (SPSS) to analyze the Pearson correlation between health literacy and treatment adherence, and health literacy and health optimism.

Health Literacy Levels

Descriptive statistics were run to better understand the health literacy of the sample. The participants had an average of 3.69 (*SD*=0.61) on their health literacy questionnaire rating. The ranges of scores were from 1.95-4.50, with over 50% of participants scoring 3.68 or below.

Treatment Adherence Levels

Descriptive statistics were computed to further understand the studies variables. The average score for the Morisky scale from 0-4 was 3.17 (*SD*= 1.23). This is considered high treatment adherence. The majority of participants **(**55.2%**)** reported

higher levels of medication adherence, receiving a score of 4 on the Morisky scale. Only 6.9% (*n*=2) of the study sample received a score of 0, which is no treatment adherence.

Health Literacy on Treatment Adherence

There was a positive, strong correlation between the health literacy as reported by the health literacy questionnaire (*M*= 3.69, *SD*=. 613), and treatment adherence as measured through the PlAnk Sum Scale (*M*=3.17, *SD*=1.23), *r*= .584, *p*=. 001. This correlation coefficient of *r*=. 584 indicates a large effect size (see Table 2). Thus, this shows that at correlation of .01 level, health literacy has a significant effect on our sample of CKD patient's treatment adherence. This correlation states that as CKD patient's health literacy increases, so does their treatment adherence rating. This results support the initial hypothesis, that there would be an association between CKD patient's health literacy levels and patient's treatment adherence.

Demographic Differences in Treatment Adherence

This study also looked at gender differences in treatment adherence using an independent samples T- test. There was not a significant difference in the treatment adherence rating between females (*M*=3.14, *SD*=1.23) and males (*M*=3.2, *SD*=1.26) scores; *t* (27) =.123, *p*= .903. Similarly, there was no significant difference between the CKD patients who were employed (*M*=2.9, *SD*=3.32) and participants who were not employed (*M*=3.32, *SD*=1.38); *t* (27) =.-.864, *p*= .395 in relation to treatment adherence.

Health Optimism Levels

Descriptive statistics were analyzed to better understand the health optimism variable. The mean score of these participants was 14.97 (*SD*= 4.08). This is considered on the lower end of the moderate optimism score. The majority of participants (41.4%)

self-rated themselves to score a 13 or below, which is considered low optimism. This means these individuals are not optimistic about their recovery and overall health. Ten participants (34.5%) scored between 14- 18, which is considered moderate optimism, and 24.1% (*n*=7) rated 19-24, which is considered high optimism (see Table 2). However, no participant self- rated a score under that was under the number 8 or over the score of 22. This means no participant had extremely low or extremely high levels of optimism.

Health Literacy on Health Optimism

There was a positive correlation between the health literacy, measured by the Health Literacy Questionnaire Scale (*M*=3.69, *SD*=.613) and health optimism, measured by the Life Orientation Scale (*M*=14.97, *SD*=4.08), *r*= .445, *p* = .016. The correlation level of .445 suggests these results represent a moderate effect size. Table 2 illustrates these results. Thus, this shows that at a correlation of .01, health literacy had a significant effect on health optimism. This supports the study's initial hypothesis that health literacy would be significantly related to health optimism. Meaning higher levels of health literacy would create higher levels of health optimism.

Demographic Differences in Health Optimism

The current study also examined the division of scores for health optimism as differentiated by gender. There was not a significant difference in the health optimism rating between females (*M*=14.5 *SD*=4.64) and males (*M*=15.4*, SD*=3.601) scores; t (27) =.586, *p*= .563. Similarly, there was no significant difference in CKD patients who were employed (*M*=16.6 *SD*=4.43) and the participants who were not (*M*=14.1*, SD*=3.73); *t* (27) =1.607, *p*= .120 on their health optimism.

Discussion

This study found significant correlations between different health variables of chronic kidney patients. In this study, health literacy was found to be associated with treatment adherence and CKD patient's health optimism. Both findings support the study's hypotheses. Thus, this study found that health literacy influences different aspects of patient's health and medical outcomes, which is similar to past findings (Chisholm, et al.,2007)

Although not many studies have looked exclusively at the effect of health literacy on health optimism, this study does support the findings of Christensen et al. (1991). Their paper found that the patients who had a more hands on experience with their CKD, or had a better understanding of their illness, had a more optimism view of their recovery (Christensen, et al., 1991). In other words, health literacy, or in this study the amount of control a patient has over their medical experience, seems to create higher levels of optimism in CKD patients, which was found in this study as well. The results of this study match those found in the past. Similarly, Costa- Requena, et al. (2014) discovered that more active coping strategies were correlated to higher levels of dispositional optimism. In regards to this study, these findings support the concept that when patients better understand their CKD, and thus can more easily cope with their diagnosis, they are more positive about their diagnosis, treatment and recovery. However, this study is one of the initial researching findings that shows the direct correlative effects of health literacy on CKD patient's health optimism. Therefore, these findings support a larger concept that the more CKD patients know about their disease, the more positive and hopeful they are about a healthy recovery.

The findings of this study also support past research looking at the effect of health literacy on patient's treatment adherence. Lai (2013) found that ESRD patients with low health literacy, struggled to self-manage their sickness and medical schedule, and thus had lower levels of treatment adherence. This study had the same findings in that the CKD patients with lower health literacy correlated to lower levels of treatment adherence. Similarly, low levels of patient health literacy in ESRD patients was correlated to higher amounts of health problems, which caused for lower treatment adherence (Fraser et al., 2013). This study took Fraser et al. findings a step further, and found the direct correlative results between these two variables. Although Kalichman, et al (2018) studied the effect of health literacy on treatment adherence in IV patients, and found that the patients who had decrease understanding of their medical information, were significantly less likely to adhere to their medical treatments. Again, this study found the same relationship in CKD patients as was observed in the HIV population.

Many studies in the past have found that low health literacy makes patients more vulnerable to health problems, which thus causes them to have lower treatment adherence (Chisholm, 2007). However, this study looked more at the direct relationship between the two variables of health literacy and treatment. Not many studies have examined this exclusive relation in CKD patients. The findings of this study relate to prior work but they also extend and further develop previous findings to help understand the connection between patient's health literacy and their treatment adherence.

There were a few limitations in this study's design. First, all of the responses to the survey were self-reported. That means that all the patients were reflecting on their own treatment adherence, health literacy and health optimism, without the second

opinion of a doctor, family member, etc. Due to this, some patients may have provided answers that were not completely valid, as they just had to select without any further details or evidence to support the validity of the statement. In other words, this study had room for the possibility of a social desirability bias, in which the participants may have answered the survey in a way that they believed would be more favorable to the public, however, potentially not the most accurately. Thus, due to the self-reporting nature of this survey, there was a potential for biases.

Another limitation to this study was the sample size. In the end, only 30 participants completed the full survey. This is a very small sample size, which could reduce the generalizability of the findings. The small sample also limited the type of analyses that could be performed to examine the complexities between these variables. The small group of participants could have been a direct effect of the characteristics of the CKD population. The patient population in this study is an incredibly sick group of people, and thus it made it hard to get participants who were able to do the study. Due to this, many people were too sick to complete the survey, some had passed away, and others did not have the time or energy to complete the study's requirements. All of this together made it difficult to collect participants and therefore, it was hard to recruit a larger sample size to get more conclusive results. Future research should use social media to blast out the survey link, as this was the fast way we could find results. Also, researchers could condense the survey making it 5-10 minutes, so it would not be as tiring or time consuming as the current measure.

Another limitation of this study is that participants who completed the study had to indicate that they were experiencing barriers to qualify for the study. Hence, patients

who face more barriers in their transplant and treatment process potentially could have lower levels of health literacy. Consequently, this may have inflated the outcomes as many of the participants had lower levels of health literacy in the first place, relative to other CKD patients who have not experienced barriers. Future research should perform a comparative study. In other words, they should look at both a population that has experienced barriers, as well as a group that has not, to see if more clearly the direct effects that high levels of health barriers have on patient's health outcomes.

This study is very important because the results are very unique, and help to further emphasize the importance of transplant awareness, as well as health literacy in the medical field. The results of this study illustrate the importance of medical providers educating patients of their diagnosis, as limited levels of health literacy do directly impact the patient's health outcomes. Patients deserve to have a full-educated briefing of their disease, so that they can have more control over their medical process. More specifically when CKD patients have low levels of health literacy, as explored in this study, they have lower health optimism and decreased treatment adherence. Both of these factors are extremely important in a patient's overall health outcome and thus can interfere with their recovery.

Another important conclusion of this study is the importance of bringing awareness to the CKD patient population. There is a very large demand for kidney transplants in this group, and as found in this study, and unfortunately, not a lot of people are donating their kidney's, which is creating a low supply. Again, this increases the number of challenges that transplant patients have to face. More research and support needs to be given to this population to help limit barriers and evoke change. In

conclusion, this research extends prior work done on CKD patients and illustrates the need for proper medical education for these patients. For example, providers could give their patients booklets or helpful guides to make sure that they are well educated on their diagnosis. Similarly, educational classes, support groups or programs could be offered to help the patients connect and learn from one another, as well as from a professional. The findings of this study further support the need for change and medical support implantation to help chronic kidney patients.

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Appendix

Section A

Table 1

Sample Characteristics of participants who completed the study

Variable	Whole sample (N = 30)
Age	(M = 47.55, SD = 13.07)
Gender	
Male	16 (51.6%)
Female	14 (45.2%)
Other	1 (3.2%)
Race	
Caucasian	17 (54.8%)
Black/African American	8 (25.8%)
Asian/Pacific Islander	1 (3.2%)
Hispanic/Latino	1 (3.2%)
Mixed	1 (3.2%)
Other	2 (6.5%)
Education	
High school or less	5 (16.7%)
Associate's degree	1 (3.3%)
Some college, no degree	6 (20.0%)
More than associate's degree, but no bachelor's degree	1 (3.3%)
Bachelor's degree	6 (20.0%)
Some graduate, no degree	5 (16.7%)
Master's degree	5 (16.7%)
Doctorate	1 (3.3%)
Employment	
Employed	10 (33.3%)
Unemployed	20 (66.7%)
Marital Status	
Single/never married	10 (33.3%)
Married/cohabit	18 (60.0%)
Divorced	2 (6.7%)
Religion	
Atheist	1 (3.2%)
Protestant	7 (22.6%)
Christian	1 (3.2%)
Baptist	4 (12.9%)
Catholic	4 (12.9%)
Jewish	2 (6.5%)
Other	4 (12.9%)
NR/NA	7 (22.6%)
Annual Household Income	
0-19,999	7 (23.3%)

20,000-39,999	4 (13.3%)
40,000-59,999	3 (10.0%)
60,000-79,999	2 (6.7%)
80,000-99,999	4 (13.3%)
100,000+	6 (20.0%)
NR/NA	3 (10.0%)
Don't Know	1 (3.3%)
Health Insurance Status	
Insured	29 (96.7%)
Uninsured	1 (3.3%)

Table 2

Summary of Correlation, Means, and Standard Deviations for Each Variable

Measure	1	2	3	M	SD
1. Health Literacy	X	.201	.445*	3.68	.613
2. Treatment Adherence	.201	X	.584**	3.17	1.23
3. Health Optimism	.445*	.584**	X	14.97	4.08

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Section B

Health Literacy Questionnaire (HLQ)
Osborne, Batterham, Elsworth, Hawkin & Buchbinder, 2013

This questionnaire contains two parts.

In **Part 1** you are asked to indicate how strongly you **disagree** or **agree** with a set of statements.

In **Part 2** you are asked to indicate how **difficult** or **easy** you find a set of tasks. Select the number that **best describes you now** using the following scale: Please ensure that you **select a number** for **every** statement or task.

Part 1 of the questionnaire starts here

Please indicate how strongly you **disagree** or **agree** with each of the following statements.

4 = Strongly Agree
3 = Agree
2 = Disagree
1 = Strongly Disagree

_____   1. I feel I have good information about health.
_____   2. I have at least one healthcare providers who knows me well.
_____   3. I can get access to several people who understand and support me.
_____   4. I compare health information from different sources.
_____   5. When I feel ill, the people around me really understand what I am going through.
_____   6. I spend quite a lot of time actively managing my health.
_____   7. When I see new information about my health, I check up on whether it is true or not.
_____   8. I have at least one healthcare provider I can discuss my health problems with.
_____   9. I make plans for what I need to do to be healthy.
_____   10. I have enough information to help me deal with my health problems.
_____   11. If I need help, I have plenty of people I can rely on.
_____   12. I always compare health information from different sources and decide what is best for me.
_____   13. Despite other things in my life, I make time to be healthy.
_____   14. I am sure I have all the information I need to manage my health effectively.
_____   15. I have at least one person who can come to medical appointments with me.
_____   16. I know how to find out if the health information I receive is right or not.
_____   17. I have the healthcare providers I need to help me work out what I need to do.
_____   18. I set my own goals about health and fitness.
_____   19. I have strong support from family and friends.

_____   20. I ask healthcare providers about the quality of the health information I
find.
_____   21. There are things that I do regularly to make myself more healthy.
_____   22. I can rely on at least one healthcare provider.
_____   23. I have all the information I need to look after my health.

Part 2 of the questionnaire starts here
Please indicate how **difficult** or **easy** the following tasks are for you **now**.

5 = Always easy
4 = Usually easy
3 = Sometimes difficult
2 = Usually difficult
1 = Cannot do or always difficult

_____   1. Find the right health care.
_____   2. Make sure the healthcare providers understand your problems properly.
_____   3. Find information about health problems.
_____   4. Feel able to discuss your health concerns with a healthcare provider.
_____   5. Confidently fill medical forms in the correct way.
_____   6. Find health information from several different places.
_____   7. Have good discussions about health with doctors.
_____   8. Get to see the healthcare providers you need to.
_____   9. Accurately follow instructions from healthcare providers.
_____   10. Get information about health so you are up to date with the best
information.
_____   11. Decide which healthcare provider you need to see.
_____   12. Read and understand written health information.
_____   13. Make sure you find the right place to get the health care you need.
_____   14. Get health information in words you understand.
_____   15. Discuss things with healthcare providers until you understand all you
need to.
_____   16. Find out which healthcare services you are entitled to.
_____   17. Read and understand all the information on medication labels.
_____   18. Get health information by yourself.
_____   19. Work out what the best care is for you.
_____   20. Ask healthcare providers questions to get the health information you
need.
_____   21. Understand what healthcare providers are asking you to do.

Life Orientation Test (LOT-R)
Scheier, Carver, & Bridges, 1994

Please be as honest and accurate as you can throughout. Try not to let your response to
one statement influence your responses to other statements. There are no "correct" or
"incorrect" answers. Answer according to your own feelings, rather than how you think
"most people" would answer.

5 – I agree a lot
4 – I agree a little
3 – I neither agree nor disagree
2 – I disagree a little
1 – I disagree a lot

_____   1. In uncertain times, I usually expect the best.
_____   2. It's easy for me to relax.
_____   3. If something can go wrong for me, it will.
_____   4. I'm always optimistic about my future.
_____   5. I enjoy my friends a lot.
_____   6. It's important for me to keep busy.
_____   7. I hardly ever expect things to go my way.
_____   8. I don't get upset too easily.
_____   9. I rarely count on good things happening to me.
_____   10. Overall, I expect more good things to happen to me than bad.

Morisky Scale (PlAnk 4 Tool)
Morisky, Green, Levine, 1986

Please respond to the following questions with either "yes" or "no."

1. Do you ever forget to take your medicine?
□   No
□   Yes

2. Are you careless at times about taking your medicine?
□   No
□   Yes

3. When you feel better, do you sometimes stop taking your medicine?
□   No
□   Yes

4. Sometimes if you feel worse when you take the medicine, do you stop taking it?
□   No
□   Yes