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The Effect of Health Literacy on Chronic Kidney Disease Patient Health Outcomes

by

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The Effect of Health Literacy on Chronic Kidney Disease Patient Health Outcomes

Abstract

Approximately 15 percent of people in the United States are living with chronic kidney disease (CKD) (USRDS, 2018). CKD is associated with significant morbidity and mortality, predominantly through increased cardiovascular risk (Taylor et al., 2017). Furthermore, patients diagnosed with CKD who display inadequate levels of health literacy may experience additional negative health outcomes (Devraj & Gordon, 2009). Awareness and knowledge regarding CKD is necessary for successful health outcomes, though adherence to medical regimens and access to information and resources. The current study seeks to enhance knowledge of health literacy among patients diagnosed with CKD. Identifying gaps in kidney-specific health literacy may help direct specific interventions to improve patient education and support. The goal of the current study is to investigate the associations between health literacy (general health literacy and kidney-specific health literacy) and patient health outcomes, such as medication adherence and barriers in access to care.

Keywords: Chronic Kidney Disease (CKD), Health Literacy, Kidney-Specific Health Literacy, Health Outcomes

Chronic Kidney Disease

CKD describes the gradual loss of kidney function. Kidneys that function properly are critical for maintaining good health given that these organs are responsible for filtering wastes, toxins, and excess fluids from blood. When chronic kidney disease reaches an advanced stage, dangerous levels of fluid, electrolytes, and wastes can build up in your body (Center for Disease Control and Prevention, 2018). Glomerular filtration rate (GFR) is a test used to check how well the kidneys are working, and is used to determine rate of kidney function loss. GFR estimates how much blood passes through the glomeruli, tiny filters in the kidneys that filter waste from the blood, each minute (Hogg et al., 2003). Stage 1 CKD describes kidney damage with normal or increased GFR (>90 mL/min), stage 2 involves kidney damage with mild decreased GFR (60-89 mL/min), stage 3 involves moderately decreased GFR (30-59 mL/min), and stage 4 is severely decreased GFR (15-29 mL/min) (Hogg et al., 2003). Stage 5 is called end stage renal disease (ESRD) with severely decreased GFR (<15 mL/min), in which the kidneys are working below 10 percent of their normal function and dialysis or transplant is needed to stay alive (Hogg et al., 2003).

Treatment for CKD is targeted at slowing the progression of kidney function loss. The treatment for ESRD involves dialysis or kidney transplantation (American Kidney Fund, 2019). Dialysis artificially removes waste products and extra fluid from your blood when your kidneys can no longer do this. In hemodialysis, a machine filters waste and excess fluids from your blood. In peritoneal dialysis, a catheter inserted into your abdomen fills your abdominal cavity with a dialysis solution that absorbs waste and excess fluids (American Kidney Fund, 2019). The preferred treatment option for ESRD is kidney transplantation, which involves surgically placing a healthy kidney from a donor into your body. Transplanted kidneys may come from decreased

or living donors – patients need to take medications for the rest of their life to keep their body

from rejecting the new organ (American Kidney Fund, 2019). The treatment plans for

individuals with CKD may be complex, involving multiple medications along with special food

and fluid regimens (Levine et al., 2018). To optimize treatment adherence, patients with CKD

must have adequate levels of health literacy in order to understand, appraise, and apply

knowledge of a complex disease process and its treatment.

Health literacy

Health literacy is defined by the Institute of Medicine as "the degree to which individuals

have the capacity to obtain, process, and understand basic health information and services

needed to make appropriate health decision" (Berkman, Davis, & McCormack, 2010, pg. 12).

Approximately 90 million adults in the United States have limited health literacy (Nielson-

Bohlman, 2004). As a potentially modifiable factor influencing individual health, it is the focus

of an expanding field of research. Groups with lower average health literacy scores include those

who are poor, members of ethnic and cultural minorities, those with less than a high school

degree, and those who are above the age of 65 (Nielson-Bohlman, 2004). In general populations,

limited health literacy is associated with poorer health, less efficient use of health care services

and higher mortality (Taylor et al., 2017).

Health literacy is a fundamental to the treatment of CKD, requiring individuals to have a

more active role in decisions and management. The estimated prevalence of limited health

literacy among adults with CKD is 23 percent (Levine et al., 2018). Low health literacy

adversely affects health outcomes in patients with CKD, as the self-management and decision-

making skills required to manage CKD may be diminished in those with low health literacy

(Taylor et al., 2017). Limited health literacy is associated with low socio-economic status (SES), comorbidity, and mortality (Taylor et al., 2016).

A growing body of research has demonstrated the association between low health literacy and worse health outcomes in the CKD population (Devraj & Gordon, 2009; Fraser et al., 2013; Tayler et al., 2017). Previous research suggests that limited health literacy is associated with certain process and health outcomes. Fraser et al. (2013) conducted a systematic review on the prevalence and associations of limited health literacy in CKD patients. The researchers found that the pooled prevalence of limited health literacy in the studies was 22.7%, signifying that approximately 1 in 5 CKD patients have low levels of health literacy. CKD patients with inadequate levels of health literacy are less likely to be referred for a kidney transplant and are less likely to complete the necessary steps in the process towards a kidney transplant (Fraser et al., 2013). The review also identified associations between limited health literacy and socio-economic factors, such as lower education attainment and lower income (Fraser et al., 2013). Additional research has identified that patients with limited health are more likely to be placed on waiting lists due to the individual's perceived inability to follow the necessary steps (Grubbs et al., 2011). Additionally, lower health literacy is associated with non-adherence to treatment plan (Tohme et al., 2017). One study examined the correlation between health literacy and treatment adherence, and its effect on clinical outcomes. The researchers found that lower levels of health literacy were independently associated with non-adherence, specifically missing hemodialysis. Treatment non-adherence was associated with an increased number of ESRD-related hospitalizations and

mortality (Tohme et al., 2017). A vast amount of research has demonstrated health literacy to be a significant predictor of health outcomes.

Health literacy is also independently associated with overall kidney function. Previous research aimed to assess the relationship between health literacy and kidney function, which was measured by estimated glomerular filtration rate (eGFR). In a participant population where 32.7 percent were classified as having limited health literacy, there was a significant relationship between health literacy and eGRF (Devraj et al., 2015). The researchers found that as an increase in health literacy was associated with an increase in eGFR score, suggesting that efforts to enhance health literacy can potentially slow the loss of kidney function (Devraj et al., 2015).

Overall, within the CKD population inadequate health literacy is associated with poorer health status (Chisholm, Fair, & Spivey, 2007). Chisholm et al. (2007) found that health literacy is a barrier to accessing, understanding, and using health information and services of the transplant process. Their results suggest that the side effects of lower health literacy result in increased hospitalization, increased costs, and thus, overall poorer health status (Chisholm, Fair, & Spivey, 2007).

Despite the emphasis of empirical study on health literacy in a patient population, few studies have addressed health literacy in the context on kidney transplantation (Kazley et al., 2015). There is limited literature regarding the impact of kidney-specific health literacy on patient outcomes. Health literacy in terms of kidney transplantation allows patients to have a basic understanding of transplant-related concepts and terms relating to their condition and treatment.

Assessing Health Literacy in CKD Patients

A vast number of tools have been developed to measure health literacy, however, limited research has been conducted in order to create a transplant-related health literacy tool. Gordon and Wolf (2009) created the Rapid Estimate of Adult Literacy in Medicine – Transplantation (REALM-T), a scale used in the current study (Gordon & Wolf, 2009). The researchers examined the relationship among health literacy, transplant knowledge, and graft function in kidney transplant recipients. Their results discovered that most kidney recipients (91 percent) had adequate health literacy. However, 81 percent were unfamiliar with at least one kidney transplant-related term (Gordon & Wolf, 2009). Limited research in CKD-specific health literacy has been a barrier in creating effective intervention programs to increase health literacy levels in CKD patient populations (Gordon & Wolf, 2009).

Despite the increasing prevalence of CKD in the United States, knowledge of kidney-specific concepts and terms is low in the general population compared to other chronic conditions (Tuot et al., 2016). One study found that 45% of CKD participants had low health literacy (Tuot et al., 2016). Although various valid methods exist, assessment of health literacy systematically within health care settings has not been routinely performed (Dageforde & Cavanaugh, 2013). This may be in part due to the limited research in kidney-specific strategies to address limited health literacy (Dagefordge & Cavanaugh, 2013). Researchers have identified the need for studies measuring health literacy among patients with CKD (Taylor et al., 2017). Research has demonstrated the importance for adequate levels of health literacy in terms of health outcomes in CKD patient population; however, studies show that a significant number of patients have inadequate levels of health literacy.

This study aims to build off previous research by examining the relationship between kidney-specific health literacy and health outcomes in CDK adults. Awareness and knowledge regarding CKD is necessary for successful health outcomes, through patient engagement and adherence to medical regimens. Identifying gaps in kidney-specific health literacy may help direct specific interventions to improve patient education and support. The goal of the current study was to investigate the associations of health literacy, kidney-specific health literacy, health outcomes in a sample of CKD patients.

In accordance with previous research that suggests inadequate levels of health literacy negatively impacts patient outcomes, the following hypotheses were developed. (Hypothesis) H1: There would be a relationship between health literacy and patient health outcomes, such as medical adherence and barriers to accessing health information and mental health care.

H2: There would be a relationship between kidney-specific health literacy and patient health outcomes (i.e., medical adherence, barriers to accessing health information and barriers to accessing mental health services).

Method

Recruitment

Participants were recruited from a pool of patients who were waitlisted, transplanted, or removed from the waiting list at an urban transplant center in the Southeastern region. Study personnel sent letters of invitation to potential participants via mail. The letters were followed up with telephone calls approximately two weeks later to solicit questions and invite participants to participate. Online recruitment methods were also performed, in which the online study link was

posted via social media platforms (Facebook, LinkedIn). Additionally, recruited participants were encouraged to provide referrals via word of mouth. This study and its recruitment methods were approved by the University of Richmond Institutional Review Board.

Participants

The survey material was administered to participants who identified as diagnosed with CKD. The current study focused on patients who faced barriers in completing the steps to be waitlisted for a kidney transplant. Participants were at least 18 years old, English speaking, and able to read and comprehend study materials. Participants under the age of eighteen, those with severe cognitive impairment, and those with language barriers were excluded from the study. Listed in Table 1 is a comprehensive description of the sample ($N = 30$). Participants were 45.2 % female ($n = 12$) and 51.6 % male ($n = 16$). The mean age was 47.55 years ($SD = 13.07$).

Materials

This study used cross-sectional data from a self-administered survey from a sample of CKD patients. The survey was administered via paper or an online survey using Qualtrics. The current study was a part of a larger study in which 7 scales were administered – Life Orientation Test (LOT), Patient Health Questionniare (PHQ), Health Literacy Questionnaire (HLQ), Rapid Estimate of Adult Literacy in Medicine – Transplantation (REAL-T), Morisky (PlAnk 4 Tool), Barriers in Access to Transplant Scale (BATS), and the Barriers to Access to Care Evaluation scale (BACE v3). The current study included the following 5 scales – Health Literacy Questionnaire (HLQ), Rapid Estimate of Adult Literacy in Medicine – Transplantation (REAL-T), Morisky (PlAnk 4 Tool), Barriers in Access to Transplant Scale (BATS), and the Barriers to Access to Care Evaluation scale (BACE v3).

Health Literacy Measures

  Health Literacy Questionnaire (HLQ). The current study used two tools in the measurement participant's health literacy levels – the Health Literacy Questionnaire (HLQ) and the Rapid Estimate of Adult Literacy in Medicine – Transplantation (REALM-T). The HLQ is a multi-dimensional tool that consists of 44 questions designed to capture people's lived experience of trying to understand, access and engage with health information and health services (Osborne et al., 2013). The HLQ was developed in consultation with individuals from the community, health practitioners and policymakers. The scale reveals health literacy strengths and weaknesses of individuals (Budhathoki et al., 2018). Questions included in the HLQ are "I feel I have good information about my health" and "I have at least one healthcare provider I can discuss my health problems with". The participant's responses were measured according 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). The HLQ has been found to be highly reliable (composite reliability ranges from 0.8 to 0.9 for each of the item scales) (Beauchamp et al., 2015). The current study had a Cronbach's alpha of 0.98 for the 44 items on the HLQ. The HLQ is displayed in Appendix A.

  Rapid Estimate of Adult Literacy in Medicine – Transplantation (REALM-T). This study used a modified version of the Rapid Estimate of Adult Literacy in Medicine (REALM) – one of the most widely used instruments to measure the construct of health literacy created by Dr. Eliza Gordon (2015). The REALM is a word recognition test used to provide clinicians with an assessment of patient health literacy. Patients read aloud as many words as they can, which are arranged in order of increasingly difficult (Gordon & Wolf, 2009). A person's REALM score is simply the number of correctly pronounced words (Dumenci, 2013). In previous research, a

Cronbach alpha was generated (0.94), which revealed a high internal consistency (Gordon &

Wolf, 2009).

The modified version, the Rapid Estimate of Adult Literacy in Medicine –

Transplantation (REALM-T), measured patients' knowledge of kidney transplantation terms

(Gordon & Wolf, 2009). The 69 terms related to kidney transplants were ordered into three

columns by increasing difficulty. The REALM-T has formerly been administered by providing

instruction for the participants to say the words on the list out loud, and then the patient's scores

depend on the number of correctly pronounced words (Gordon & Wolf, 2009). In this study, the

participants were instructed to mark each transplant-related term instead of pronouncing the

terms out loud. As shown in Appendix B, the patients were instructed to mark each term that

they recognized in relation to kidney transplantation. Scores between 60 and 69, 45 and 59, and

44 or less are considered representative of adequate or good health literacy, marginal health

literacy, or inadequate or low health literacy (Kazley et al., 2015).

Health Outcome Measures

Patient outcomes were measured by using three tools – Morisky scale (PlAnk 4 Tool),

Barriers in Access to Transplant Scale (BATS), and the Barriers in Access to Care Evaluation

(BACE v3). Using multiple measures of patient outcomes in this study allowed for a higher

validity of results and a more precise understanding of the relationship between health literacy

and health outcomes.

The Morisky scale (PlAnk 4 Tool). This is a validated medication non-adherence

assessment designed to estimate the risk of medication non-adherence (Morisky, Green, &

Levine, 1986). The Morisky scale has been cited in over 70 articles since its publication in 1986,

and has been used for research involving many different chronic conditions. The total Morisky

score is based on patient self-reported responses to four yes or no questions (Morisky et al.,

2008). The scale is designed to indicate factors associated with failure to adhere to a medication

regimen. Each item is measuring a specific medication-taking behavior – "Do you ever forget to

take your medication?", "Are you careless at times about taking your medication?", "When you

feel better, do you sometimes stop taking your medication?", and "Sometimes if you feel worse

when you take your medicine, do you stop taking it?". The Morisky scales is scored from zero,

representing the lowest level of medication adherence, to four, the highest level of medication

adherence. The Morisky medication non-adherence scale is demonstrated in Appendix C. In

previous research, the reliability of this scale was found to be 0.6 (Morisky, 1886). The current

study had a Cronbach's alpha of .79 for the 4-item scale.

The Barriers in Access to Transplantation Scale (BATS). Developed by Dr. Camilla

Nonterah, this scale was designed to better understand which patients are at the greatest risk of

experiencing barriers in their attempt to get a kidney transplant. In order to assess the hardships

and struggles that the patients undergo during the ESRD battle, participants were asked to reflect

on their own transplant experience through a series of 59 questions (Nonterah et al., n.d.).

Questions included in the BATS include "I know a lot about kidney transplants", "the

information my doctors and nurses gave me about transplant was easy to understand", and "I

have a hard time reading information about transplant". The participant's responses were

measured by instructing them to indicate the degree to which they agree or disagree with each

statement using a Likert scale (5 = strongly disagree, 4 = mildly disagree, 3 = agree and disagree

equally, 2 = mildly disagree, 1 = strongly disagree). The current study used 14 of the 60

questions in the BATS tool. The 14 items assessed patient's barriers in accessing information

related to their treatment. The BATS questions used in this study can be located in Appendix D. The current study had a Cronbach's alpha of .70 for the 14 items on the BATS.

   The Barriers in Access to Care Evaluation (BACEv3). Health outcomes were also assessed using the Barriers to Access to Care Evaluation (BACEv3; Clement & Thornicroft, 2011). The current study only used the survey section from the BACEv3, which allows the researchers to assess barriers patients face in accessing mental health services. The BACEv3 instrument was created as a self-completed four stage psychometric measure accessing the barriers of dealing with, and seeking out mental health services and care. The goal of the survey was to find interventions to decrease these setbacks, and make care more accessible to the mentally ill. The current study used the survey section from the BACEv3, which consists of 30 separate items, including 12 stigma related questions (Clement & Thornicroft, 2011). Questions on the BACEv3 include "I have many mental health conditions that make it hard to complete my evaluation for transplant", "Concern about what my family might think, say, do or feel", and "Having problems with childcare while I receive professional care". The tool was organized in a way in which participants were given questions ranging from "this has stopped, delayed or discouraged me A LOT", to "this has stopped, delayed or discouraged me NOT AT ALL," to address things that may have discouraged or delayed the individuals from getting professional care for their mental health problems, or from continuing to get help (Clement & Thornicroft, 2011). It has strong internal consistency ($\alpha = 0.90$) and test–retest reliability ($r = 0.92$) (Clement et al., 2012). The current study had a Cronbach's alpha of 0.97 for the 30 items on the BACEv3. The survey section from the BACEv3 used is displayed in Appendix E.

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Results

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Data Analytic Plan

Following the collection of the cross-sectional survey results, the data was used to perform statistical tests in order to gain a better understanding between both health literacy and kidney-specific health literacy and health outcomes. IBM Statistical Package for the Social Sciences (SPSS) for statistical analysis was used for the statistical analyses. A Pearson Correlation was conducted between each health literacy variable (health literacy and kidney-specific health literacy) and each health outcome variables (medication adherence, barriers in accessing mental health services, barriers in accessing information).

Primary Analyses

Descriptive statistics, including mean and standard deviation, were computed for each of the health literacy variables. The average score of health literacy on a scale of one to five was 3.69 ($SD = 0.61$). The average number of kidney-transplant words recognized according to the REALM-T was 53.97 out of a total of 69 terms ($SD = 13.93$).

The results from the REALM-T demonstrated that 20% of the participants ($n = 6$) had inadequate transplant-related health literacy, 30% ($n = 9$) marginal health literacy, and 50% ($n = 15$) good health literacy. Though majority of the participants identified as having good health literacy, 96.7% ($n = 29$) of the participants were unfamiliar with at least one kidney transplant-related term.

Mean and standard deviation computations were also completed for the health outcome measures. The average medication adherence score was 3.17 on a scale of one to four ($SD = 1.23$). The average score for barriers in access to mental health services was 0.95 on a scale of one through five, five demonstrating the greatest number of barriers ($SD = 0.94$). Lastly, the average score for barriers faced in access to information was 1.65 on a scale of one through five, five demonstrating the greatest number of barriers ($SD = 0.59$). Overall, the participants had a

relatively high average of medication adherence and faced few barriers in accessing mental

health services and information.

The Morisky Scale (PlAnk 4) measured levels of medication adherence scored zero

through four, which represents the lowest level of medication adherence to the highest level of

medication adherence. The results show that majority of the patients (55.2%) had the highest

level of medication adherence.

Main Analyses

There was a significant relationship between health literacy and each of the health

outcome measures. Health literacy had a significant positive correlation with medication

adherence with a large effect size (r (29) = .584, p < .001). Health literacy also had a significant

negative relationship with barriers in access to information with a large effect size (r (29) = -

.640, p < .001) and a significant negative correlation to access to mental health services (r (29) =

-.403, p = .030), which is a moderate effect size. There results indicate that as a participant's

level of health literacy increases, their medical adherence increases and barriers in care decrease.

Furthermore, there was a significant positive correlation between kidney-specific health

literacy and barriers in access to information (r (29) = -.408, p = .025) with a moderate effect

size. However, no significant correlation was found between kidney-specific health literacy and

medication adherence (r (29) = .005, p = .981) or kidney-specific health literacy and access to

mental health services (r (29) = -.278, p = .145). These results indicate that as a participant's

level of kidney-specific health literacy increases, they experience less barriers in accessing

information relating to their condition; however, no significant relationship was found between

kidney-specific health literacy and medication adherence or barriers in accessing mental health

services.

A Pearson Correlation conducted between health literacy and kidney-specific health literacy, identified that there was no significant relationship between the two health literacy measures (r (29) = .146, p = .442). This result indicates that there is no correlation between general health literacy and kidney-specific health literacy within this patient population. The correlation matrix of the Pearson Correlation between study variables is demonstrated in table 2.

Discussion

The current study examined the relationship between health literacy and health outcomes, with the purpose of enhancing knowledge of health literacy among patients diagnosed with CKD. In accordance with previous research that suggests inadequate levels of health literacy is negatively associated with patient outcomes, the following hypothesis were developed. (Hypothesis) H1: There would be a relationship between health literacy and patient health outcomes such as medical adherence and barriers to accessing health information and mental health services.

H2: There would be a relationship between kidney-specific health literacy and patient health outcomes.

In accordance with previous research, the first hypothesis was supported by the results. In the current population of CKD patients, there was an association between health literacy and health outcomes. Health literacy was found to have a significant relationship with medication adherence, barriers in access to mental health services, and barriers in access to information. The significant positive correlation between health literacy and medication adherence, suggests that as level of health literacy increases, the level of medication adherence increases. Therefore, patients will the highest level of health literacy are more likely to adhere to their medication and treatment plans. The results of the current study have been demonstrated in previous research.

Studies have demonstrated that lower health literacy is associated with non-adherence to medical and treatment plans (Tohme et al., 2017; Gordon & Wolf, 2009, Kalichman et al., 2008).

Furthermore, the significant negative relationship between health literacy and barriers in access to mental health services, suggests that as levels of health literacy increases, the number of barriers faced in regards to mental health treatment decreases. Patients with the highest levels of health literacy, are less likely to face barriers when accessing mental health services. Lastly, the significant negative correlation between health literacy and barriers in access to information, suggests that as levels of health literacy increases, then barriers in access to information decreases. Patients with the highest levels of health literacy, are less likely to face barriers when accessing information in regards to their condition. The results of the current study are in line with previous research, which has suggested a significant relationship between health literacy and patient health outcomes. Research shows that health literacy is a barrier to accessing, understand, and using health information and services during the kidney transplantation process (Chisholm, Fair, & Spivey, 2007). Health literacy has been found to have a direct effect on health outcomes in patients with CKD, but also patients with a variety of other chronic conditions (Devraj & Gordon, 2009).

However, the results did not support our second hypothesis, that there would be significant relationship between kidney-specific health literacy and health outcomes. Kidney-specific health literacy did have a significant correlation with one of the health outcome variables (barriers in access to information), suggesting that as the level of health literacy increases, the number of barriers faced in accessing information decreases. These results suggest that patients with the highest level of health literacy, face fewer barriers when accessing information in regards to their condition. However, no significant relationship was found between kidney-

specific health literacy and medication adherence or kidney-specific health literacy and barriers in access to mental health services. These results suggest that participants' levels of kidney-specific health literacy are not associated with their level of medication adherence or on the number of barriers faced when accessing mental health services.

Specific to the current study, the insignificant relationship between kidney-specific health literacy and health outcomes could be attributed to the study's methods. The REALM-T, which measured participant's level of kidney-specific health literacy, was primarily developed to enable clinicians and other health educators to assess the patient's ability to understand health advice. The REALM-T is a word recognition test used to provide clinicians with an assessment of patient health literacy, in which the patient reads aloud as many terms related to kidney transplants as they can (Gordon & Wolf, 2009). The tool was not created to be used as a self-report measure, as it was in the current study. The tool is therefore best considered as a screening tool for clinicians, rather than providing a comprehensive assessment of health literacy (Fraser et al., 2012). As the REALM-T was used as a self-report measure in which the participants were instructed to mark each transplant-related term instead of pronouncing the terms out loud to a physician, it may explain the results that are inconsistent with previous research.

Implications from this study signify the value or early assessment and detection of health literacy level among CKD patients, as inadequate health literacy may negatively affect health outcomes. Previous research suggests that an understanding of health literacy in terms of kidney transplantation is an asset that improves capacity for self-care, facilitate navigation of the health system, and improve the quality of patient-provider interactions (Fraser et al., 2012). Health care providers should intervene with better patient education materials to improve patients' health literacy, which should improve patients' health outcomes. Patient education materials should

cater to patients' education level and could be culturally sensitive (i.e. bilingual). Patient

education materials are necessary but not sufficient – education materials should also be

continuous with providers assessment to make sure their patients understand the information.

There is also a need to recognize the limitations of the study's methods. The sample size

serves as a significant limitation of the current study. The small sample of participants decreases

the power of the study. The sample was gathered primarily from a single-center which also

reduces generalizability of the findings. As a result of the small sample size, only Pearson

Correlations were conducted between each variable, which did not allow for understanding the

complex relationships between these variables.

Furthermore, each tool used in the current study collected information through a self-

report measure. When collecting information through a self-report, people are often biased when

they report on their own experiences. Individuals may consciously or unconsciously be

influenced by social desirability bias. The social desirability bias causes participants to report

experiences that are considered to be socially acceptable or preferred.

Further research assessing the effect of health literacy on patient outcomes within the

CKD should be aimed at a larger sample size. A large sample of CKD patients will allow for

more valid and reliable results. Additionally, aims of further research should examine mediators

and moderators between the health literacy and health outcomes variables. Researchers can

examine disparities in levels of health literacy and health outcomes by demographics (i.e. gender,

age, race, socioeconomic status, education level).

The results from this study may be used to formulate further research and highlight the

need for creating a self-report kidney-specific health literacy tool. Knowledge of kidney

transplant related concepts and terms is low in the general population (Tuot et al., 2016), yet only

one tool has been created to measure kidney-specific health literacy. The REALM-T was developed to be administered by clinicians (Gordon & Wolf, 2009). There is a need for creation of a self-report kidney-specific health literacy tool. Even though self-report measures open up the potential for social desirability bias, self-report tools are an easy and fast way to collect data. The inconsistent kidney-specific health literacy results from this study exemplify the need for additional health literacy tools within the CKD patient population.

Furthermore, the results suggest the need to develop and evaluate interventions to increase patient's level of health literacy. Health literacy has been shown to be correlated with many health outcomes. Feasible interventions, such as clear communication techniques, clear health education materials, clear medication labeling, and self-management support programs, can improve health outcomes for patients with CKD. There is also a need to assess health literacy of people with pre-stage CKD. Health literacy is important throughout the whole care pathway in CKD. Having the appropriate tools to identify pre-stage CKD patients with inadequate levels of health literacy, will help direct specific interventions to improve both levels of health literacy, and therefore, improve patient health outcomes.

The goal of this study was to investigate the associations of health literacy, kidney-specific health literacy, and health outcomes in a sample of CKD patients. The results suggest participant's health literacy has a significant effect on health outcomes such as medication adherence and barriers to accessing care. Though only one health outcome tool demonstrated a significant relationship with kidney-specific health literacy, there is need for further research and development of kidney-specific health literacy measurement tools. Enhancing health literacy among patients diagnosed with CKD through patient education materials and other resources is

important, as awareness and knowledge regarding CKD is necessary for successful health

outcomes.

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Tables

Table 1.
Sample Characteristics

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	4	5	M	SD
1. Health Literacy						3.69	0.61
2. Kidney-Specific Health Literacy	.146	–				53.97	13.93
3. Medication Adherence	.584**	.005	–			3.17	1.23
4. Barriers in Access Mental Health	-.403*	-.278	-.329	–		0.94	0.94
5. Barriers in Access Information	-.640*	-.408*	-.534**	.323	–	1.65	0.59

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

Appendix A.

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

Select the number that **best describes you now** using the following scale: Please ensure that you **select a number** for **every** statement or task.

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.

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.

Appendix B

Rapid Estimate of Adult Literacy in Medicine (REALM-T) Transplantation
Gordon, 2015

Please mark the following terms that you recognize in relation to kidney transplantation.

List 1	List 2	List 3
Team_____	Function_____	Procedure_____
Graft_____	Disease_____	Urethra_____
Risk_____	Transplant_____	Rapamune_____
Test_____	Biopsy_____	Prednisone_____
Rate_____	Drug levels_____	Hemorrhage_____
Match_____	Immune_____	Medicare_____
Drug_____	Prograf_____	Ultrasound_____
Kidney_____	Urine_____	Systolic_____
Fever_____	Obesity_____	Potassium_____
Sugars_____	Cellcept_____	Immunosuppressant_____
Organ_____	Infection_____	Medication_____
Renal_____	Chronic_____	Diastolic_____
Blood_____	Surgeon_____	Nephrologist_____
Donor_____	Protein_____	Cholesterol_____
Fluid_____	Antibody_____	Creatinine_____
Acute_____	Vascular_____	Recipient_____
Tissue_____	Survival_____	Triglycerides_____
Delay_____	Sodium_____	Cyclosporine_____
Failure_____	Edema_____	Hypertension_____
Virus_____	Rejection_____	Noncompliance_____
Orally_____	Dialysis_____	Antirejection_____
Ulcer_____	Trough level_____	Toxicity_____
	Blood pressure_____	Blood urea nitrogen_____
		Sensitization_____

Appendix C

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?
2. Are you careless at times about taking your medicine?
3. When you feel better, do you sometimes stop taking your medicine?
4. Sometimes if you feel worse when you take the medicine, do you stop taking it?

Appendix D

Barriers in Access to Transplantation Scale (BATS)
Nonterah (n.d.)

Directions: Below is a series of statements which describe the experiences of kidney patients considering getting a transplant. Reflect on your own experiences *(current or past)* and indicate the degree to which you agree or disagree with each statement below by using the following scale:

5 = Strongly Agree
4 = Mildly Agree
3 = Agree and Disagree Equally
2 = Mildly Disagree
1 = Strongly Disagree

1. I know a lot about kidney transplants.
2. The information my doctors and nurses gave me about transplant was easy to understand.
3. I want a kidney transplant because I know it is better than dialysis.
4. I do not understand why I need to go through an evaluation for transplant.
5. I do not have enough information about kidney transplants.
6. It is hard to understand what my doctors are saying sometimes.
7. I do not understand a lot of the information about transplants because of the words and terms used.
8. I have a hard time reading information about transplant.
9. I don't know where to get information about kidney transplants.
10. I cannot find information on kidney transplants because I do not have the Internet.
11. No one in my family or friend group knows about transplants.
12. I cannot remember all the information I was given about kidney transplants.
13. The information I was given about kidney transplants was too much at once.
14. I do not understand why I have to take a lot of tests for a transplant.

Appendix E.

Barriers to Access to Care Evaluation (BACE v3)
Clement & Thornicroft, 2011

Below you can see a list of things which can stop, delay or discourage people from getting professional care for a mental health problem, or continuing to get help. By professional care we mean care from such staff as a GP (family doctor), community mental health team (e.g. care coordinator, mental health nurse or mental health social worker), psychiatrist, counsellor, psychologist or psychotherapist.

Indicate the degree to which **any of these issues has <u>ever stopped, delayed or discouraged you</u> from getting, or continuing with, professional care for a mental health problem?**
by using the following scale:

> 5 = This has stopped, delayed or discouraged me **A LOT**
> 4 = This has stopped, delayed or discouraged me **QUITE A LOT**
> 3 = **I'M NOT SURE** if this has stopped, delayed or discouraged me
> 2 = This has stopped, delayed or discouraged me **A LITTLE**
> 1 = This has stopped, delayed or discouraged me **NOT AT ALL**
> 0 = This is **NOT APPLICABLE** to me (e.g. if it is a question about children and you do not have children)

1. Being unsure where to go to get professional care
2. Wanting to solve the problem on my own
3. Concern that I might be seen as weak for having a mental health problem
4. Fear of being put in hospital against my will
5. Concern that it might harm my chances when applying for jobs
6. Problems with transport or traveling to appointments
7. Thinking the problem would get better by itself
8. Concern about what my family might think, say, do or feel
9. Feeing embarrassed or ashamed
10. Preferring to get alternative forms of care (e.g. traditional / religious healing or alternative / complementary therapies)
11. Not being able to afford the financial costs involved
12. Concern that I might be seen as 'crazy'
13. Thinking that professional care probably would not help
14. Concern that I might be seen as a bad parent
15. Professionals from my own ethnic or cultural group not being available
16. Being too unwell to ask for help

17. Concern that people I know might find out
18. Dislike of talking about my feelings, emotions or thoughts
19. Concern that people might not take me seriously if they found out I was having professional care
20. Concerns about the treatments available (e.g. medication side effects)
21. Not wanting a mental health problem to be on my medical records
22. Having had previous bad experiences with professional care for mental health
23. Preferring to get help from family or friends
24. Concern that my children may be taken into care or that I may lose access or custody without my agreement
25. Thinking I did not have a problem
26. Concern about what my friends might think, say or do
27. Difficulty taking time off work
28. Concern about what people at work might think, say or do
29. Having problems with childcare while I receive professional care
30. Having no one who could help me get professional care