

# Phosphate Binder Adherence and Perceived Cardiovascular Risk Among Young Adult Patients Receiving Maintenance Hemodialysis

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**Abstract**

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**Background:** Cardiovascular disease is the leading cause of death and disability among patients with End-Stage Renal Disease (ESRD). Hyperphosphatemia is an independent cardiovascular risk factor in patients undergoing maintenance hemodialysis. Most patients are on a class of medication called Phosphorus Binders, which they take with meals and snacks to absorb the phosphorus naturally present in their food. Unfortunately, not all patients who are prescribed binders will take them. This study is designed to explore the barriers to phosphate binder adherence in young adult patients on hemodialysis. We hypothesized that, among patients aged 18-44, this may be due to an inaccurate or incomplete understanding of their susceptibility to an adverse cardiovascular event, such as stroke or heart attack.

**Methods:** Participants were recruited from hemodialysis clinics operated by a large, for-profit dialysis provider in Western Washington. Eligible patients who consented to participate in the study were interviewed 1:1 by the researcher. Selection criteria for eligible participants were as follows: 1) the

participant had been on maintenance hemodialysis at least 90 days prior to the start of the study, 2) the participant was between the age of 18-44 years old at the time of interview, 3) the patient was oriented to person, place, and time, 4) the patient spoke fluent English, and 5) the patient was prescribed a phosphorus binder to take with meals.

**Results:** Seven women and ten men completed the interview. Participants ranged in age from 20-41 years old. Approximately one-third of the participants identified increased risk of heart attack or stroke as a result of hyperphosphatemia. However, three-quarters of the participants were able to identify at least one negative health consequence, most often calciphylaxis and bone disease. The remaining patients verbalized understanding that high phosphorus was bad for their health, even if they could not identify a specific health outcome. Roughly half of the patients made statements that demonstrated high perceived risk to hyperphosphatemia-related disease outcomes and the other half made statements to suggest low perceived risk or no perceived risk. Physical, psychosocial, financial, and other barriers to optimal adherence were explored to create an informed picture of adherence variables.

**Conclusions:** The results of this study support that most young adult patients on dialysis are aware that hyperphosphatemia has serious negative health consequences for renal patients. This study suggests that knowledge of deleterious outcomes related to hyperphosphatemia does not readily translate to optimal phosphorus management in young adults on dialysis and that psychosocial, clinical, and healthcare delivery variables all play a role in hindering optimal adherence.

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## INTRODUCTION

As of 2012 over 450,000 people with End Stage Renal Disease (ESRD) in the United States were on dialysis.<sup>1</sup> Approximately 59,000 dialysis patients were between the ages of 19-44 by the end of December 2012, the latest year for which such data is available. Cardiovascular disease is the leading cause of death and disability among ESRD patients, including young adult patients.<sup>2</sup> While ESRD is a complicated chronic condition with many facets to disease management, one independent cardiovascular risk factor is elevated serum phosphorus (sPO(4)) levels.<sup>3-4</sup>

Phosphorus is derived from the diet. It is essential for normal cell function as it forms the major cellular energy molecule adenosine triphosphate (ATP) and is used in many metabolic processes.<sup>3</sup> Best practice guidelines for mineral bone disease management specify 3.0-5.5 mg/dL as the target goal phosphorus range.<sup>3</sup> People with ESRD are not able to maintain phosphorus homeostasis and can develop unhealthy sPO(4) levels, defined as a value above 5.5 mg/dL.

Elevated serum phosphorus causes calcium to be drawn out of bones and circulate in the serum.<sup>5</sup> The excess calcium causes vascular smooth muscle cells to mineralize, adopting the hardness and inflexibility characteristic of bone tissue. This process is termed vascular calcification. There are two types of vascular calcification, arterial medial calcification (AMC) and arterial intima calcification (AIC). While AIC is typically observed in older adults with a history of atherosclerosis, AMC has been observed in young and middle-aged adults even in the absence of other conventional risk factors.<sup>6</sup> AMC has been found to be an independent marker for all-cause and CVD-related mortality for ESRD patients.

Calcified blood vessels cannot effectively deliver blood and nutrients to body tissues, causing the heart to work harder to pump blood through the stiff vessels. The left ventricle enlarges, which leads to heart failure.<sup>7</sup> High sPO(4) also contributes to increased intact parathyroid hormone (iPTH) levels and disordered calcium metabolism, which contribute to bone and vascular disease. Calciphylaxis in the extremities can cause tissue necrosis and amputation may become necessary.<sup>8</sup>

In addition to its contribution to cardiovascular disease, high phosphorus negatively impacts the patients' quality of life.<sup>9</sup> Elevated sPO(4) levels cause bone pain and extreme skin itchiness. Severe

dietary restrictions are advised and include common foods such as dairy products, chocolate, nuts and nut products, deli meats, and many foods that contain preservatives.<sup>10</sup> Physical symptoms and the exclusion of common foods from their diet increase patients' perception of the burden of kidney disease on their everyday life.

Most patients take a phosphorus binder, a medication taken with meals and snacks to absorb the phosphorus naturally present in their food.<sup>11</sup> The phosphate binders and their captured phosphate load are excreted when the patient has a bowel movement. The importance of phosphate binder adherence cannot be over-stated as taking binders is independently associated with decreased mortality compared to not taking binders even when phosphorus is maintained within the acceptable range of 3.7-5.5 mg/dL.<sup>12</sup> The binder dosage is typically tailored to account for the patient's dietary intake and sPO(4) levels.

Unfortunately, not all patients who are prescribed phosphate binders will actually take them. Previously published reviews examining this topic have found a mean self-reported non-adherence rate of 50-67%.<sup>13</sup> Most determinants of adherence fall into one of three categories: demographic, clinical, and psychosocial.<sup>14</sup> Demographic variables include age, gender, income, education, and ethnicity. Clinical variables include time on dialysis, type of dialysis, presence of other comorbidities, side-effects, dosing frequency, and laboratory outcomes.

Psychosocial issues include health knowledge, beliefs, attitudes, coping skills, family and/or partner support, pill burden, and perceived burden of chronic disease. The degree to which psychosocial issues hinder adherence may be more profound for younger adults who have responsibilities that older adults do not have, such as raising children and working outside of the home, as well as different mechanisms for coping. The most commonly cited psychosocial barriers are medication cost, transportation challenges, medication side effects, and health beliefs.

Data from the Dialysis Outcomes and Practice Patterns Study (DOPPS), a prospective cohort study of hemodialysis practices in twenty countries including the United States, showed higher odds of non-adherence among younger patients.<sup>15</sup> A systematic review by Karamanidou and colleagues found that 46% of studies included in the review cited younger age as being a risk factor for non-adherence.<sup>16</sup>

They hypothesized that younger patients may have more difficulty coping with a chronic disease than older patients and/or younger patients may have less structure in their lives due to balancing other responsibilities such as childcare and employment.

A study by Ishisaka and colleagues of adherence to antihypertensives also found less adherence among younger adults. The authors suggested this might be due to a diminished perception of the treatment as "necessary" or a decreased perception of chronic disease compared to older adults.<sup>17</sup> Many young adults also participate actively in a social life. A qualitative study evaluating dietary adherence in dialysis patients found that the respondents would not follow dietary advice due to fear of social stigma.<sup>18</sup> By association, taking medications with food could contribute to that fear of stigma among peers.

Qualitative studies in this area exist in the literature but few have focused specifically on young adults. An Australian study by Williams and colleagues that included, but was not limited to, young adult patients with diabetic kidney disease found that patients did not trust that they needed all of the medications they were prescribed.<sup>19</sup> Patients also based decisions on which medication to take based on whether or not they could "get away with" not taking them, assigning greater priority to some medications than others. Patients felt that health conditions were treated with the addition of new medications, despite personal preferences to be on as few medications as possible. This suggests that patients experience "unresolved conflict" between themselves and their health care providers, who tended to prioritize medication access and adherence when talking to patients and downplayed the patients' perceptions of adverse side effects.<sup>18, 19</sup>

In order to explore the challenges faced specifically by young adults, this study focused on medication adherence behaviors with patients between 18-44 years of age. We hypothesized that younger patients may have an inaccurate or incomplete understanding of their susceptibility to an adverse cardiovascular event, such as stroke or heart attack. It may be difficult for patients in their prime to imagine having cardiovascular disease, yet it is the main cause of death for ESRD patients between 25-44.<sup>20</sup> If patients do not perceive themselves as being susceptible to a negative outcome, they may not take the necessary preventive measures, such as managing hyperphosphatemia. A diminished perception of

susceptibility can also lead to emotion-centered coping skills that lead the patient to dismiss or devalue physical symptoms of hyperphosphatemia such as itchiness, joint pain, and red, itchy eyes.

This study does not distinguish between intentional non-adherence, such as choosing not to fill a prescription, and unintentional non-adherence, such as forgetfulness. Both types of non-adherence will have negative health effects and patients must develop self-management skills to address any and all barriers that are preventing them from following their prescription. It is essential that renal health care professionals understand the reasons for non-adherence and support the patients in overcoming these barriers.

## **THEORETICAL BASIS**

The theoretical basis for this study was the Health Belief Model (HBM).<sup>21</sup> A theory-based approach to health behavior research offers many advantages that include the following: offering a perspective on behavior change and development of interventions, providing a guide to analysis, and supporting generalizability.<sup>22</sup> The HBM endeavors to predict why a person will perform a health behavior by looking at the primary concepts of "susceptibility, seriousness, benefits and barriers to the behavior, cues to action, and self-efficacy."<sup>23</sup> With the exception of cues to action, the aforementioned constructs are all individual perceptions a patient may have about a given health behavior. Whether or not he or she adopts the behavior is influenced by modifying factors that include age, gender, ethnicity, personality, socioeconomics, and knowledge. Cues to action may influence a person's behavior but this construct has proven difficult to study systematically.<sup>21</sup>

The HBM is appropriate for this study for several reasons. Patients who do not perceive themselves to be at risk for a cardiovascular event may not be engaged in medication adherence behaviors that prevent the said event or they may weigh other factors more heavily in deciding what action to take. As described in a review of phosphate binder adherence variables by Karamanidou and colleagues psychosocial variables, while the least studied in binder-adherence research, are more likely to be significantly associated with non-adherence than demographic or clinical variables.<sup>16</sup> Two-thirds of articles reviewed that related health beliefs and medication adherence found significant relationships.

Therefore, a model that explores the patients' beliefs is central to understanding reasons for binder non-adherence.

Previous reviews of HBM studies have found that perceived susceptibility was a strong predictor of preventive health behavior.<sup>23</sup> Therefore this is an appropriate construct to explore as diligent adherence to phosphate binders is a preventive behavior meant to avoid cardiovascular and bone disease. Perceived barriers have been found to be the most powerful predictor of behavior. Therefore a theoretical basis that explores susceptibility and barriers is well-suited for evaluating this behavior. The interview schedule generated for this project is centered on the core HBM constructs (see Appendix).

## **METHODS AND TIMELINE**

This was a descriptive qualitative study of young adult hemodialysis patients in Western Washington. This study was approved by both the Human Subjects Division at the University of Washington and DaVita Clinical Research. Immediately following approval, seven clinics operated by a large dialysis provider were identified as suitable for recruitment. Since the principal investigator (PI) is also an employee of the organization, all clinics where she had worked in the past three years were excluded due to potential bias.

After selecting the participating clinics the PI presented a webinar to the in-center renal dietitians to explain the purpose of the study and elicit their support (see Appendix). The research activities of the renal dietitian (RD) colleagues was limited to informing prospective subjects about the availability of research, providing subjects with information about the research, providing prospective subjects with information about contacting the PI for information or enrollment, or obtaining prospective subjects' permission for investigators to contact them, and releasing information to the PI.

After the webinar training, the RDs identified eligible participants in their centers. Selection criteria for eligible participants were as follows: 1) the participant has been on maintenance hemodialysis at least 90 days prior to the start of the study, 2) the participant is between the age of 18-44 years old at the start of the study but not older than 44 by the time the study ends, 3) the patient is oriented to person,

place, and time, 4) the patient can speak fluent English, and 5) the patient is prescribed a phosphorus binder to take with meals.

The RDs then asked potential subjects if they would be interested in participating in a study conducted by a Master's degree student at the University of Washington. A short script was provided for the dietitian to use when approaching the potential subject. The script asked for permission for the investigator to contact the patient to review the study in more detail, either chair-side during treatment or via telephone. Each RD also received a flyer to hang in the lobby of her unit.

The goal was to have at least 20-25 participants.<sup>24</sup> Previous qualitative studies on medication adherence in older adults have found saturation after 15 interviews.<sup>25</sup> Out of 20 patients who consented to participate, 17 completed the interview. Of the three patients who did not complete the interview, one changed her mind after the interview started. One patient arranged a time to be interviewed via telephone but was unavailable at the appointed time and did not respond to voice messages left to reschedule. One patient signed the opt-in and informed consent documents but declined to schedule the interview on three separate occasions, citing feeling tired and depressed as reasons he did not want to participate. After the third refusal the investigator ceased to pursue the subject.

The remaining 17 participants were given the option to be interviewed chair-side during treatment, before or after treatment in a private office or conference room in the center, or via telephone. Sixteen patients completed the interview chair-side. One participant began the interview chair-side and then completed it in a private office after his dialysis treatment terminated approximately half way through the interview. All interviews were completed by the primary investigator (LO). The investigator met with the patient, usually within a week of receiving their contact information. All subjects provided written informed consent. Participation in the study was purely voluntary. Subjects did not receive any form of compensation for participating.

For the first six interviews the investigator met with the participant and obtained informed consent, then proceeded to do the interview immediately after obtaining consent. The investigator then decided to spend more time building rapport with the participants to encourage them to share more freely.

For the remaining eleven interviews, the investigator met with the participant to provide informed consent. The PI also made general conversation during the first meeting to establish rapport with the participant. Then the participant and investigator decided on a date and time together to complete the actual interview. All remaining eleven interviews were scheduled within one to two weeks of the initial meeting. Demographic variables were recorded at the end of the interview session. This helped to reduce the formality of the interview session and encourage a natural flow of conversation.

Each interview was audio-recorded and transcribed. The recordings and transcripts were labeled numerically in the order that they were completed solely to match each recording to its transcript. There were no links to personal identifying information in the transcripts. Any mention in the audio-recording of potential identifiers, including names of nephrologists or dialysis centers, was transcribed as XXXX.

Once transcribed, the PI developed prominent categories were developed via open coding and content analysis. The main outcome measures were statements that relate to patient understanding of susceptibility to an adverse cardiovascular event as a result of binder non-adherence. The categories were then interconnected and used to create a larger picture of adherence behaviors to generate theoretical propositions.<sup>23</sup>

Demographic characteristics including age, sex, ethnicity, and educational level were obtained to describe the patient population. Participants self-reported their first date of dialysis (FDOD), which was used to estimate the number of months they had been on dialysis at the time the interview was completed. Some participants reported having received a transplant in the past. The number of months with a functional transplant was subtracted from the FDOD to determine a cumulative length of time on dialysis. The PI began asking about prescription insurance coverage as a proxy for income level after interview 5 after it became readily apparent that financial strain was a determinant of medication adherence for the first few participants. While the primary goal of this study was not evaluating financial barriers per se, the PI deemed it an important part of the patients' overall experience with barriers to adherence.

This study design is different from other designs because it allowed for exploration of the complexities of medication adherence behavior from the point of view of the patient via ethnographic

interviews. While it is hoped that this undertaking will yield ideas for interventions, there were no interventions delivered for the study subjects.

## **RESULTS**

### *Participant demographics*

Seven women and ten men completed the interview. Participants ranged in age from 20-41 years old. Seven participants identified as White, six as Black, two as Latino, one as Pacific Islander, and one as Native American. Educational attainment was as follows: Four subjects had not completed high school; four completed high school but did not pursue additional formal education; one subject completed trade school; seven subjects completed at least some college; and one subject completed college. No subject had an advanced degree.

With regards to occupational status, six subjects were employed full-time at the time of the interview. Eight subjects were medically disabled and/or unemployed. One patient was medically retired from the military. Two subjects were full-time students at local community colleges. Participant demographics are summarized in the Appendix.

All subjects were on in-center hemodialysis for at least 90 days as a criterion for participating in the study. The shortest length of time on any dialysis modality for any one subject was 5 months, with 4 patients total on dialysis for one cumulative year or less at the time of the interview. The longest cumulative time on dialysis for any one subject was 216 months.

Though all subjects were currently on in-center hemodialysis, some had previous experience with other forms of renal replacement therapy. Two subjects had previously been on peritoneal dialysis (PD) and one subject was recently referred for PD. One patient tried PD in the past without success. One patient had previously been on home hemodialysis (HHD) and one patient was interested in pursuing HHD. Four subjects had previously received a kidney transplant. In calculating length of time on dialysis, time spent (in months) with a functional transplant was subtracted from the FDOD. Time spent on a modality other than ICHD was included in total time spent on dialysis.

All patients were prescribed a phosphate binder as a criterion for participating. Seven participants were prescribed Renvela alone for their phosphate binder needs. Five patients were prescribed Phoslo only. One patient was prescribed generic calcium acetate. One patient was on Fosrenol. One patient was prescribed both Fosrenol and Phoslo with each meal. One patient was prescribed only Tums, and one patient was prescribed generic calcium acetate but reported he was more likely to use Tums due to cost.

Pill burden was ascertained by asking the patient how many prescriptions they took each day, and then asking how many individual tablets they took per day. The number of tablets per day ranged from 4 to 30. Patients were also asked their binder prescription for meals and snacks; ten were prescribed 1 to 2 binders per meal, four were prescribed 3 to 4 binders per meal, and two were prescribed 5 binders per meals. Approximately half of all patients also had a smaller binder prescription for snacks.

#### *Perceived benefit of phosphate binders*

Once patients identified what phosphate binder they take, the interviewer asked why they were prescribed that medication. Most subjects perceived phosphorus control as the primary benefit of taking their phosphate binders. Fourteen of the seventeen participants used terms such as “lower my phosphorus,” “take phosphorus down,” and “block phosphorus.” Of the remaining three patients, one patient stated the primary reason was to increase calcium, although he was not on a calcium-based binder. One patient stated the reason was to “take chemicals out of [pt’s] body” but could not specifically identify which chemical(s). One patient did not know what phosphate binders did and paused during the interview to ask a staff member at his clinic.

#### *Perceived threat of hyperphosphatemia*

Immediately after they identified the reason for taking phosphate binders, subjects were asked about the health consequences of high phosphorus. Since most patients identified phosphorus control as the reason for taking binders, this question was usually phrased as “why is phosphorus control important?” Two patients that did not identify phosphorus control as a function of binders did mention avoiding high phosphorus foods so the interviewer used this as a segue to discuss perceived consequences

of high phosphorus. One patient who stated binders remove “chemicals” from her body was asked about the consequence of those chemicals, as phosphorus levels were not raised by the subject as a concern. For the one patient who did not know what phosphate binders did, the PI asked “what happens if you don’t take your Renvela?” because he did know the name of the medication.

Sixteen subjects stated high phosphorus was undesirable. The most commonly identified health consequence was calciphylaxis, identified by 8 subjects. While most subjects did not use the medical term calciphylaxis they conveyed the concept using words such as “crystallization,” “sores,” “skin damage,” and “deposits.” The next most common health consequence was bone disease or damage, identified by 6 subjects. Five subjects identified CVD as a health consequence of hyperphosphatemia.

**Box 1.** Exemplar quotations from patients for perceived threat

**Cardiovascular Disease**

*“[High phosphorus] will affect your blood vessels. I think it will close them off.”*

*“Phosphorus...causes problems with your heart, like if you have a high result.”*

*“[high phosphorus] seizes up the arteries.”*

*“[phosphorus] can start the calcium build-up in the heart.”*

*“...your body can’t have too much phosphorus in it because...it makes your heart weak. You can have cardiac arrest.”*

**Calciphylaxis**

*“If you get high phosphorus you get damage. It can eat your legs up...and it won’t go away.”*

*“The benefit [of binders] is to keep your phosphorus lower so it doesn’t cause crystallization to your muscles and your organs inside.”*

*“[High phosphorus] will harden your skin. I think it will ruin your limbs.”*

*“There’s deposits that you can get. They have pictures out there [in the lobby] that will scare the bejeezus out of you.”*

**Bone disease**

*“When I don’t take [Renvela] it’ll weaken my bones.”*

*“That stuff [phosphorus] will mess up your joints....[if] you break a leg or something and it won’t heal properly.”*

*“You can be at risk for brittle bone disease if you keep your phosphorus high.”*

*“[Renvela] keeps my phosphorus in range so I won’t end up being itchy or red eyes or...calcium deposits? Something to do with my bones.”*

Seven subjects identified itchiness as an outcome. While not medically urgent, itchiness negatively affects patients’ quality of life. One subject described itchiness from hyperphosphatemia as follows:

*“Once you feel [itchiness from high phos] you don’t want to feel like that anymore. It’s worse than any mosquito bite I’ve ever had or chicken pox.”*

Four patients could not identify a specific negative health outcome. However, all four made a statement to the effect that high phosphorus was undesirable. For example, one subject described the health threat as *“[High phosphorus] is gonna do damage in your body.”* Similarly, another subject reported that without his Renvela *“I can get medical problems.”*

*Perceived susceptibility*

After identifying a health consequence of hyperphosphatemia, patients were then asked to evaluate their personal susceptibility to the outcome. Eight subjects made statements to suggest low or moderate perceived risk and 9 subjects made statements to suggest high perceived risk. Subjects that were not able to identify a health consequence of hyperphosphatemia were categorized as having Low perceived risk because it was unlikely that they would perceive themselves as being at risk for a consequence they were not aware of.

Subjects who did identify a specific outcome were asked to respond to the question "how likely do you think it is that [identified outcome] would happen to you?" Their answers are in **Box 2**.

**Box 2.** Patient statements of perceived susceptibility to a hyperphosphatemia-related adverse outcome.

Low or Moderate Perceived Susceptibility	High Perceived Susceptibility
<p><i>Subject #2: "It's hard for me to say because I don't have problems like that."</i></p> <p><i>Subject #3: Well you have to get really high</i></p>	<p><i>Subject #5: "Oh, it will happen again."</i></p> <p><i>Subject #6: "I think it's extremely likely."</i></p>

<p><i>phosphorus and not control it and keep it high.</i></p> <p><i>Subject #9: I guess I would say not likely but I don't see what would separate me from anyone else. When I hurt my ankle I started thinking about my negligence. About taking my binders and keeping my levels where they should be. But as far as every day I don't think about the long-term. Who does?</i></p> <p><i>Subject #17: I try to think that it's not going to happen. [pt laughs] It's in the back of my mind, probably like 25%. But if I try to maintain the best that I can I don't think it's going to happen.</i></p> <p><i>Subjects #1, #4, #10, and #16 could not identify a specific health outcome related to hyperphosphatemia.</i></p>	<p><i>Subject #7: "[High phosphorus] can have really bad effects if it's not managed. It will harden your skin. I think it will ruin your limbs. I don't like to make myself feel bad so I try to stay on top of that stuff."</i></p> <p><i>Subject #8: "I've had issues with my phosphorus so it's planted in my head to take [binders]."</i></p> <p><i>Subject #11: "High phosphorus will calcify joints and other parts of the male anatomy [pt has a serious look on his face]. I hate binders, but I gotta take 'em."</i></p> <p><i>Subject #12: It's very likely I believe.</i></p> <p><i>Subject #13: "I ain't no athlete but I do like working. I don't need to be falling and breaking no bones and then it won't heal right. Interviewer: It sounds like that's something that's really important to you. Pt: Yes."</i></p> <p><i>Subject #14: "Compared to pre-heart attack, I probably think about all of my medications a little more seriously now." Pt also rated likelihood of experiencing adverse outcomes as 5 out of 5, where 1 was not likely and 5 was very likely.</i></p> <p><i>Subject #15: It's definitely something you worry about. If you didn't worry about it you're kind of lying to yourself.</i></p>
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### *Perceived barriers*

As previously discussed, most patients reported that phosphate binders control phosphorus and all patients stated that not taking phosphate binders could lead to an undesirable outcome, even if they could not specifically identify what that outcome was. However, most patients reported difficulty taking binders as prescribed. Only two patients stated they took binders as prescribed 100% of the time. One admitted that it had taken him several years on dialysis before he reached this level of adherence. Three patients estimated their adherence at 80% or above.

Some patients did not estimate their adherence with a percentage but made statements that indicated missing doses such as:

*“If I have to miss the Renvela I just miss it.”*

*“It just depends on my labs but mostly [Sensipar and Renvela] are not really important.”*

*“...the Renvela are the pills I have the most trouble taking.”*

*“[Binders and hyperphosphatemia] are very important but I don’t seem to act that way sometimes.”*

Such statements warranted exploration of the apparent disconnect between perceived susceptibility to an undesirable health outcome and barriers to medication adherence behavior. The most commonly cited reason for not taking binders was forgetting to take them. Ten participants cited forgetting as a barrier to consistent adherence, with three noting trouble with memory in general. One subject lamented, *“I’m only 39. I shouldn’t be forgetting this much stuff.”* Another subject attributed his memory issues specifically to dialysis, stating *“Dialysis causes short-term memory problems. There’s no doubt about it.”* Three patients reported time constraints, described as *“being in a rush”* or *“always on the go,”* contributed to a tendency to forget binders. Three subjects also described forgetting to take binders because it was not yet a habit to take a medication with every meal or snack.

For some patients, eating was also done in a rush or on the go. Subject 12, a full-time student and mother of three young children, explained *“I still forget because I’ve already eaten and I’m thinking about something else.”* Patients who described eating food away from home were also likely to describe forgetting to bring binders with them or take them when they ate, even if they did bring them.

For other patients, stopping to take the phosphate binder was viewed as a disruption to their usual activity. In describing challenges taking medication at her place of employment, one subject explained *“the only one [work] causes problems with is Phoslo. Because if I’m on the run and eat something on the go, I have to take time out of my day to get them and take them.”*

Interestingly when probed about what might contribute to forgetting six patients stated that they really did not want to take the phosphate binder. Participant 5 was the first subject whose interview hinted at such a distinction:

*Subject: I just forget to take my medications a lot.*

*Interviewer: What contributes to forgetting?*

*Subject: I really don't want to take them. Some of them make you sick; they make you nauseous.*

Immediately after interviewing Subject #5, a question was added to the interview schedule to investigate the circumstances of forgetting in an effort to determine if it was true forgetfulness or avoidance. With the new question in place, more participants expressed similar sentiments. Reasons identified for not wanting to take the binder indicated that patients, in general, dislike at least one attribute of the binder itself. One participant explained:

*Subject: "You would think me taking [medications] all my life it would be hardwired in my brain to take them. But sometimes I forget.*

*Interviewer: You described taking some medications with food [meaning binders]. Do you ever forget those?*

*Subject: I could say yes but that would be a lie. Sometimes I just don't take them.*

*Interviewer: Can you tell me about that?*

*Subject: They're gross! They're binders, so they're chalky. Just gross."*

Another participant echoed a similar sentiment: *"But it's also kind of weird. Eating something and then putting something chalky in your mouth."*

Regardless of whether or not the patient reported forgetting medication, all patients had complaints about at least one aspect of their prescribed phosphate binder. The most commonly cited barrier was size, especially among patients taking Renvela. Nearly all patients on Renvela complained about the size, with several describing them as *"big horse pills."* Renvela cannot be cut into smaller pieces but it can be dispensed in powder form, though no patients in this study were taking it that way. Two of six patients taking Phoslo also described it as being too big.

Nearly all patients on a chewable binder complained of the texture. Tums, chewable calcium acetate, and Fosrenol were all described as *"chalky," "gross," "horrible,"* and/or *"nasty."* A few patients described having problems with appetite at baseline and felt that binders diminished the experience of the meal. They did not have much of a desire to eat in general, and taking binders made the thought of eating that much less appealing. Interestingly, no patients reported side effects from binders that would deter

them from taking them. Only one patient reported that he would never take more than two binders with a meal because it might cause constipation.

Two patients also complained about the quantity of binders prescribed per meal. Participant #4 described her feeling about Renvela as “...*how many that I have to take. It turns you off to taking it.*” For all patients except one, their binder made up 30% or more of the number of daily tablets they took per day. For eight subjects phosphate binders made up 50% or more of their daily tablets. Subject 6 reported “*I think I forget [to take Renvela] because I’m taking so many other pills.*”

Several patients complained of financial barriers to binders, both with and without prescription insurance. Three patients had experienced a loss of insurance coverage at some point in their time on dialysis. The most common reason was losing a job and thereby losing employment-based health insurance. Participants who experienced this situation described their prescription binders as being prohibitively expensive. One patient reported not being eligible for prescription benefits because he only worked part-time. Two patients reported relying on samples from the nephrologist’s office to get through a period of not having insurance coverage for binders.

Some patients with insurance also had financial difficulty filling phosphate binder prescriptions. For one patient the binders were only partially covered but left a co-pay of several hundred dollars. One subject described a high co-pay that was usually manageable, but after his wife lost her job they elected to cut back on prescription spending. Unfortunately this patient did not qualify for a patient assistance program. During the interview, the interviewer realized another patient was eligible for an assistance program but she did not know the program was in existence.

Social variables also proved to influence binder adherence. Patients reported that social support at home helped with taking binders. Eight patients reported that a family member directly assisted them with medication management. Some laid out pills in a case or on the table for the patient. Some prompted patients to take their binders by asking if they had taken them with a meal. Others picked up prescriptions for the patient. Two patients reported that a family member brought binders to them when they forgot them at home.

Conversely, two patients did not have any social support and discussed their lack of support in the interview. These patients both had busy schedules; one worked and one was a full-time student. They both lived with non-related roommates who played no part in their medication management. Both reported taking their binders only about half as often as prescribed. Patient #17 described his lack of support as follows: *“I’m a single male so it’s not like I have a girl that coaxes me to take [Renvela] when I’m out and about.”*

Social influences from family and significant others were cited as encouraging adherence. Interestingly, the opposite was true for influence from peer groups and potential romantic partners. The following statements illustrate this effect:

*“I would drink and go out and party and just be like everybody else. And at the end of the day I would take my pills but on top of already being intoxicated. The majority of my friends were out partying and doing whatever they wanted and I just wanted to be a part of that.”*

*“Many times I’ve been out to lunch with clients or at work and I forgot and I don’t have Tums. And they don’t realize why I’m not eating. But if it’s a business lunch that’s not going to help anything. It makes everything awkward. It makes people wonder what’s going on. And you don’t want to tell anyone new that you’re sick and you don’t want to be treated a different way. That is a major deal.”*

*“Sometimes I wouldn’t want to take it at work...mostly just in front of coworkers. Or at a restaurant or something. I wouldn’t want to pop out 2 or 3 pills...and that’s even with people who know I’m on dialysis...I definitely wouldn’t take it out on a date.”*

All patients who described excellent adherence at present described a period of time, sometimes lasting for years, before they made medication adherence a consistent habit. These patients had personally experienced undesirable side effects, such as itchiness, red eyes, or a bigger wake-up call such as a heart attack, which spurred them to be more diligent with binders.

## **DISCUSSION**

### *Implications for direct patient care*

The goal of this study was to shed light on how young adult patients on dialysis perceive their susceptibility to an adverse cardiovascular event and if this perception informs their decision to take or not take phosphate binders. Most participants were not aware of their increased risk for an adverse

cardiac event and by extension had little to no perceived threat of such an outcome. However, 14 of 17 patients could identify at least one specific health consequence of hyperphosphatemia. The remaining three patients made statements that demonstrated they understood hyperphosphatemia to be deleterious to renal patients, even if they did not know exactly why. These findings are consistent with other published studies in this area.<sup>26</sup>

Despite the knowledge that taking a phosphate binder lowered phosphorus, and that high phosphorus was undesirable, all participants described challenges with phosphate binder adherence. It is evident from the interviews that knowledge of high phosphorus and its consequences is not sufficient to encourage adherence. This is consistent with earlier studies that demonstrate knowledge of dietary phosphorus restrictions do not necessarily produce adherence to low phosphorus diets in patients either.<sup>27</sup> Within the context of overall ESRD management, the patients' perceptions of barriers revealed medication-specific, clinical, social, and health care service factors that contribute to medication adherence.

The top three most deterring features of phosphate binders themselves were size, taste/texture, and dosing. Nearly every patient made a complaint about one of these features of their binder and said this was a deterrent to taking the medication. With binders, most patients have to take multiple tablets per meal, and take them as often as they eat. It was no surprise that pill burden was also mentioned as a challenging feature of this medication regimen. A recent study of 233 hemodialysis patients in three different geographic areas of the United States by Chiu et al found that over half of the study subjects were prescribed 20 or more daily pills.<sup>28</sup> For three-quarters of the participants in this study, binders made up 50% or more of their daily tablets.

The results from this study were consistent with other studies that have found the dosing frequency of phosphate binders also hinders adherence. A study by Coleman and colleagues found that in comparison to once-daily pill regimens, those with 3 and 4 times daily dosing patients were 13.5% and 19.2% less adherent, respectively.<sup>29</sup> Dosing frequency for these participants may have been complicated by the amount of time spent outside of the home, especially for the young adults who were in school or working. Eight patients reported they often forget to bring binders with them when they go out and

binders are not readily accessible when they are out. Of the few patients that reported success with taking binders when out and about they all stated they kept binders “everywhere” including in their cars, in the homes of friends and family members, at work, and on their person in a purse or pill carrier.

Additional challenges identified by patients were cost and insurance coverage. Patients with ESRD may have difficulty holding steady employment or holding employment that offers health care benefits. This can lead to gaps in insurance coverage. Prescription-strength phosphate binders are prohibitively expensive without insurance. Even under some insurance plans, patients may still have high copays. During the first few interviews it became readily apparent that financial barriers were a significant determinant of patients’ adherence to phosphate binders. While assistance programs exist to help patients obtain access to binders, patients may not know about the programs or they may not qualify. Similarly, health care providers may not know if patients need assistance unless the patient discloses financial hardship.

Forgetfulness was another commonly cited barrier. It was discussed as a barrier to binder adherence and as a problem in general. This study suggests there may be more to forgetfulness than meets the eye. On one hand, forgetfulness may indicate a cognitive problem with memory functions, which could impact remembering to take medications. Cognitive impairment has been observed in patients with ESRD in previous studies, though most of these have been in older adults.<sup>30</sup>

Interestingly, a study by Drew and colleagues explored the relationship between elevated fibroblastic growth factor-23 (FGF-23) and cognitive performance in 263 hemodialysis patients.<sup>31</sup> FGF-23 is a bone-derived hormone that regulates phosphorus homeostasis. It increases as kidney function declines. Drew and colleagues found that younger age was one of many variables that were significantly associated with higher FGF-23 levels in univariate and multivariate analyses. After adjusting for age, sex, and education, higher FGF-23 level was associated with worse memory function. Young adults may have more problems with memory as a result of higher FGF-23 and this area warrants further study.

Memory may also be affected by depression.<sup>32</sup> More than half of the participants in this study cited psychosocial challenges related to being on dialysis. Three patients reported taking anti-depressants.

Several others reported losses of friends, independence, jobs, and/or significant others, which could lead to depression.

Forgetfulness may also be a byproduct of less structure in daily activities. Five patients described challenges with taking phosphate binders because of “being in a rush,” “always being on the go,” and/or eating a meal and then “already thinking about the next thing” they had to do. Patients described stopping to take binders as an interruption to their activities. Subjects that were students or employed were more likely to make such comments. Health care providers may need to assist patients with developing effective cues to take binders.

On the other hand, forgetfulness might be used as a blanket term that includes medication avoidance behavior. When asked about the circumstances of forgetting their medication, several patients stated that they sometimes chose not to take the phosphate binder, even though they knew they should. These patients all cited a specific attribute of the binder (taste, size, texture, etc) as a reason they were averse to taking it, even though all of the patients knew that high phosphorus was bad for them. In this situation, the perceived benefit of the binder did not outweigh risks of hyperphosphatemia. When a patient cites “I forget” as a reason for not taking binders, this should serve as a flag for a health care provider to investigate the circumstances of forgetting and discern if there an actual problem with memory recall or if perhaps forgetting is being used to describe an avoidance-based coping mechanism.

Social support proved to be an important variable in binder adherence. Sources of social support identified in this study included significant others, parents, family members, and coworkers. These individuals prompted the patient to take binders, brought the binders to the patient when he/she forgot at home, or refilled a prescription. Health care professionals should treat lack of family support and social isolation as red flags for clients that will have a harder time taking binders as prescribed. Further, every effort should be made to educate the primary support person(s) for patients on hyperphosphatemia and medication adherence.

It was previously hypothesized that patients with young children at home might have more difficulty managing a medication regimen. Interestingly, the opposite was found to be true. Four

participants had children (under age 18) living the home and all reported a way in which their child(ren) aided in medication adherence. For three participants, the children often prompted them to take binders by asking them if they had taken their pills when they ate together as a family. One participant reported that he had a daily ritual of taking his medication with his son while his son took a vitamin. Another participant reported that her children were a primary motivator in getting her high phosphorus levels under better control.

Social influences have the potential to improve adherence. Several patients had direct support from a family member or significant other that directly impacted their ability to take binders as prescribed. However, there is a need for providers to remain sensitive to the changes in interpersonal dynamics that occur when a family member or spouse tries to help the patient stay on track. Providers should gently guide the efforts of support persons such that the patients feel encouraged as opposed to chastised. When looking at social influences of dietary adherence for dialysis patients, Palmer and colleagues heard from many patients who complained that family members policed their diet and scolded them when they made poor choices.<sup>18</sup> Such conflict could lead to patients feeling infantilized and create tension in their relationship, and would not serve to encourage the patient's adherence.

It is also important to note that influences from peer groups may deter adherence. Three subjects described how they were dissuaded from taking binders in front of others. Such statements indicate that patients are choosing peer acceptance over disease management, even though they know that they need to take the medication.

#### *Implications for health services delivery for renal patients*

The most basic finding from this study is that knowledge of an adverse outcome did not necessarily translate to perceived risk of the outcome. Nearly all patients knew high phosphorus was not good for them but most reported some degree of nonadherence, either to binders, diet, or both. Only five patients were aware of their increased risk of cardiovascular disease. This represents an area of opportunity for

renal health care providers to adequately communicate CVD risk to patients. These findings provide a basis for a future survey to quantitatively assess the major themes in a similar population.

A surprising finding among the study participants was the number of patients who were diagnosed with ESRD without prior knowledge of kidney disease. Nine patients reported being diagnosed with ESRD, most of which were diagnosed in the hospital after a period of weeks or months of feeling ill. These patients started dialysis on an emergent basis. Four of these patients had known risk factors for kidney disease, namely childhood/young adult onset of hypertension or diabetes. Of the remaining 8 patients, two were diagnosed with late-stage kidney disease and had less than one year between first becoming aware of their kidney disease and the start of dialysis. These results were consistent with published reviews on nephrology referral which found that around one third of patients do not see a nephrologist until they have fewer than four months before starting dialysis.<sup>33,34</sup>

This finding is worth noting because it suggests that most patients were blindsided by their ESRD diagnosis. Patients who are diagnosed with ESRD are more likely to report having a difficult time adjusting emotionally. Curtis and colleagues described a stage of Initial Crisis when patients are suddenly diagnosed with a serious medical illness, which leads to emotion-focused coping strategies such as anxiety, anger, sadness, and fear.<sup>35</sup> A qualitative study by Monaro and colleagues found that patients react initially to dialysis with a profound sense of loss that permeates most aspects of their lives including personal relationships, employment, freedom, and spontaneity.<sup>36</sup> The authors concluded that many patients come to dialysis unprepared for what lies ahead. The participants in this study also described losses similar to those in the Monaro study and reported feeling anxious and afraid when told they would need to start dialysis.

A further complication of the Initial Crisis stage is that patients may not be psychologically ready to learn about ESRD self-management. They do not retain information as easily as those who are in a stage of acceptance with their disease.<sup>35</sup> Patients could also be suffering from depression. It is estimated that up to one third of patients with ESRD experience depression, which has been associated with feelings of helplessness, hopelessness, and reduced self-efficacy.<sup>37,39</sup> All of these feelings could compromise

medication adherence. Renal healthcare providers must be aware of the patient's degree of acceptance and tailor approaches to patient education appropriately.<sup>38</sup>

Three patients in this study self-reported denial as a reason for not taking phosphate binders early on in their disease process. Denial is a defensive emotion-focused coping strategy that is associated with failure to seek and adhere to medical recommendations, and may explain why non-adherence behaviors are so often observed in the ESRD population.<sup>39</sup> Patients in this study who voiced acceptance of their disease also voiced higher adherence rates to phosphate binders than those who reported currently struggling with depression and anxiety. A quarter of participants admitted to needing to take antianxiety medication just to make it through their treatment session.

Patients who come to dialysis unprepared may also feel less control over their disease process. A study by Williams and Manias found that patients managing coexisting diseases frequently experimented with their medication habits as a means of having control over their illness.<sup>40</sup> Therefore, patients may decide to take more or fewer binders than prescribed. Patients with low health literacy were more likely to report this behavior, despite not being able to fully explain what the medication did, and they would often do so without telling their physicians. One patient in this study reported making his own changes to his home hemodialysis regimen without telling his physician and elsewhere in the interview lamented his lack of control stating *"It's nice to have any ounce of control I can get. It's basically non-existent elsewhere."* While exploring perceived control was beyond the scope of this study, this observation is in line with current literature and suggests an opportunity for further study.

The transition to dialysis might not be so traumatic if patients had timely referral for nephrology care. While ESRD in young adults is rare, and CKD itself is relatively silent until its latest stages, there were still missed opportunities for nephrology referral in this cohort, as evidenced by four patients with known risk factors for kidney disease who were still surprised by their diagnosis. These patients were under medical care for hypertension and/or diabetes but reported being unaware that these conditions predisposed them to CKD.

Multiple studies have documented a significantly increased risk of mortality and hospitalization, delayed referral for transplant, and decreased likelihood of home dialysis modality options in patients referred late to nephrology care.<sup>33, 34, 41</sup> Patients also miss out on the opportunity to be referred for nutrition education and case management services to facilitate a smoother transition to life on dialysis. Only one patient in this study was referred to a dietitian for chronic kidney disease medical nutrition therapy, despite evidence that suggests diet changes in CKD stage 3 and 4 can delay disease progression.<sup>42</sup> Efforts to improve early nephrology referral and referral for interdisciplinary pre-dialysis education are areas that warrant further study.

This study also points to a need to investigate how much time nephrologists are dedicating to discussing hyperphosphatemia with their CKD and ESRD patients. A study by Fadem and colleagues found that ESRD patients generally prefer physician-based education.<sup>43</sup> Within the span of a nephrology appointment the physician must address a host of issues, including dialysis access, anemia, blood pressure, fluid management, transplant, and recent laboratory values. Some of these issues have higher risk of morbidity and mortality than others. This list does not include the issues the patient may want to discuss. For this reason, and possibly others, there may not be sufficient time spent thoroughly discussing long-term risks associated with hyperphosphatemia.

While patient education is not limited to nephrology clinic visit, it is important for nephrologists to reinforce education given by other interdisciplinary team members, which include nurses, dietitians, and social workers. In this study thirteen patients identified their physicians as their go-to source for questions about binders. Six patients also reported talking to their nurse about binders. Conversely, only three patients reported talking about binders with their dietitians, even though dietitians with this dialysis provider meet with patients at least monthly and routinely discuss binder adherence in the context of phosphorus management.

This could reflect patients' perceptions of physicians as the authoritative voice on all medication-related matters. It certainly points to a need for physicians to reinforce that phosphorus management is important and encourage patients to discuss hyperphosphatemia with their interdisciplinary team at

dialysis so patients will be receptive to education from other disciplines. Best practices in interdisciplinary communication among members of a dialysis team may be an area that warrants further study.

Dialysis providers may also consider how to improve patient education in the dialysis center. Several patients in this study reported feeling exhausted at the end of treatment. Reasonable effort should be made to counsel the client at the beginning of his or her treatment when the patient is most alert. Previous studies have demonstrated that cognitive performance is the same within the first hour of dialysis compared to one hour before dialysis, suggesting that the client's ability to learn the material being presented in the first hour will not be compromised by the demands placed on the body by dialysis itself.<sup>44</sup> This may not be true later into the patient's treatment session. If unable to meet with patients at the start of dialysis, consider setting up an office appointment with the patient and/or caregiver. Educators might also consider a phone appointment to follow up on items discussed in-center.

Qualitative studies evaluating diet education have found that patients prefer multiple problem-solving sessions with their provider as opposed to "one-off" education sessions.<sup>17</sup> They wish to be part of the decision-making process with their clinical team, rather than being scolded for non-adherence. It is therefore important for providers to approach medication adherence as a problem to be solved with the patient and their supportive caregiver(s).

## **STRENGTHS AND LIMITATIONS**

This study had a few limitations to consider when interpreting the results. Firstly, as a qualitative study the PI takes a certain degree of liberty when deciding what to transcribe and what not to transcribe. In the beginning of the interview the PI asked a few rapport-building questions, such as the participant's hometown or what they did the prior weekend. During the interview there were a few tangential conversations as patients shared anecdotes of other aspects of their lives. These rapport-building conversations and anecdotes were left untranscribed. A notation was made in the transcript to indicate a side conversation had occurred and included the time in the recording during which the conversation

occurred, such as “[pt discusses pets from 15:36-16:04].” Only conversation related in some way to medication, dialysis, or challenges as a patient with ESRD were included in the full transcripts. Therefore one must interpret the results with an awareness that the patients’ responses are being viewed with the investigator’s lens.

There was a risk of bias if the researcher asked explicitly about phosphorus binders during the interview. The dialysis provider has a strong focus on phosphorus management as part of its delivery of care. Patients are aware of the importance of taking binders, even if they choose not to. Therefore, when asked about binders, the patients might have reported greater adherence and fewer challenges than what they actually experience because they might have an idea of the kinds of answers their care providers are looking for. The University of Washington approved a Waiver of Elements of Consent as part of the IRB approval that allowed the researcher to omit the exact purpose of this study (phosphorus binder adherence) and frame the purpose as “medication management” instead. Patients were debriefed as to the study’s true purpose using an approved letter at the conclusion of the interview.

There was a risk of bias if the participants knew the investigator is a renal dietitian employed by their dialysis provider. Therefore, the researcher was identified only as a student from the University of Washington. This risk was mitigated by excluding clinics in which the investigator had worked in a professional capacity in the past three years. The PI was introduced as a student to staff members in the participating clinics so that they did not accidentally reveal that she was an employee.

Another limitation of this study was selection bias. Per the in-center renal dietitians, some patients who have challenges with various aspects of their treatment adherence were approached for participation and did not wish to be interviewed. Clients who chose not to participate may experience greater challenges with adherence, including coming to dialysis treatment, taking medications, and following their prescribed diet. It is possible that patients who were willing to be interviewed were also more adherent with disease management recommendations, including medication-taking behavior. Therefore this study may not accurately depict the experience of patients who really struggle to follow medical advice related to their kidney disease.

A possible limitation was that patients might not wish to be interviewed due to concerns about privacy. Interviews that were conducted chair-side took place while the patient was undergoing treatment at the same time as other patients. The researcher was hopeful that this would not be too much of an issue because patients are used to routinely discussing their care with providers during treatment, including dietitians, nurses, social workers, and nephrologists. Patients were offered the option to be interviewed in a conference room or over the phone. All participants who elected to participate in the interview chose to be interviewed during treatment.

A limitation to this study is that participants must be able to understand and communicate in English. This may limit the applicability of the results to dialysis clinics that serve a large population of non-English speaking young adult patients. An additional limitation is that patients are being pulled from a private health care organization that does not typically accept uninsured patients. Therefore, the interviews may not capture the challenges to medication adherence experienced by self-pay patients. Furthermore, none of the participants were homeless, which might limit applicability for clients experiencing homelessness.

An additional limitation is that most patients, 10 out of 17, were on a relatively low binder prescription of 1-2 binders per meal. Therefore, this cohort may perceive a lesser degree of overall pill burden, which could impact adherence. It could also indicate that these patients have lower nutritional intake, as binder prescription should ideally be tailored to actual food intake. Several patients reported fair to poor appetite. While this study did not look at markers of nutritional status, in a dialysis center setting certainly nutritional status should be evaluated as part of the larger clinical picture that includes medication adherence. Lastly, only one patient was on Fosrenol, which has been reported to have higher rates of side effects than other types of binders.<sup>45</sup> Therefore, this study does not fully depict binder-specific barriers that patients on Fosrenol may experience.

## CONCLUSION

In summary, this study showed that most young adult patients on dialysis are aware that hyperphosphatemia has serious negative health consequences for renal patients. However, just over half of the participants perceived themselves as being personally at risk for any adverse outcome related to hyperphosphatemia. Only five patients perceived themselves as being at risk specifically for an adverse cardiovascular event. Surprisingly, although all patients knew that high phosphorus was undesirable, more than half self-reported binder nonadherence and/or high phosphorus. This study suggests that knowledge of deleterious outcomes related to hyperphosphatemia does not readily translate to optimal phosphorus management in young adults on dialysis and that psychosocial, clinical, and renal healthcare service delivery systems all play a role in hindering optimal adherence. Future studies may evaluate these relationships quantitatively and focus on young adults.

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*“In your report, tell them if they’re on dialysis, keep an open mind. Always stay positive. It ain’t the end of the world.” – Participant #13*

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# Appendix

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## Participant Demographics

Subject	Age (yr)	Gender	Ethnicity	Length of time on dialysis (months)	Binder prescription	Education	Occupation	Insurance Type (if known)
1.	39	M	Caucasian	12 months	REVELA 1 q meal	Trade school	Medically disabled	Medicare
2.	39	M	Caucasian	36 months	TUMS 500 mg q meal	College	Employed full-time	Private
3.	29	F	Pacific Islander	12 months	REVELA 5 q meal	11 <sup>th</sup> grade	Medically disabled	Unknown
4.	20	F	Caucasian	18 months	REVELA 3 q meal	11 <sup>th</sup> grade	Medically disabled	Unknown
5.	38	F	Caucasian	66 months	CAL ACETATE 2 q meal, 1 q snack	High school	Employed full time	Unknown
6.	39	M	African American	19 months	REVELA 2 q meal	High school	Medically disabled	Medicare
7.	33	M	African American	144 months	REVELA 4-5 q meal, 3 q snack	High school	Employed full-time	Medicare
8.	25	F	Caucasian	18 months	PHOSLO 4 q meal, 3 q snack	Some college	Employed full-time	Medicare
9.	24	M	Caucasian	72 months	FOSRENOL 1-2 q meal PHOSLO 1-2 q meal	11 <sup>th</sup> grade	Medically disabled	Medicare/ Medicaid
10.	40	M	Caucasian	11 months	PHOSLO 1 q meal	GED	Unemployed	Medicaid
11.	36	M	Native American	16 months	PHOSLO 3 q meal	Some college	Employed full time	Private
12.	36	F	African American	83 months	FOSRENOL 1000 mg q meal	Some college	Student	Unknown
13.	40	M	African American	25 months	REVELA 2 q meal, 1 q snack	Some college	Medically retired	VA
14.	41	F	African American	216 months	REVELA 2 q meal, 1 q snack	Some college	Employed full time	Private
15.	35	M	Latino	48 months	PHOSLO 3 q meal, 1-2 q snack	Some technical training, currently pursuing GED	Unemployed since 2012	Medicaid and Medicare
16.	22	F	Latina	5 months	PHOSLO 2 q meal	Some college	Unemployed after ESRD dx	Medicare
17.	35	M	African American	44 months	CAL ACETATE (1-2q meal) or TUMS (4-5q meal)	Some college	Student	Unknown

## Patient Questionnaire

Hello \_\_\_\_\_,

Thank you for taking the time to talk with me today. I am interested in learning about your experiences as a hemodialysis patient with a focus on how you manage your medications. Dialysis patients are often taking many different kinds of medications and I'm very interested in how taking medications fits in with your daily life.

There is a lot of research on challenges that older adults face with taking medications, but there is less research on young adults. Therefore, your experiences are very valuable. They can help health care providers understand the challenges that young adults face on dialysis. This can help your providers educate other patients about managing kidney disease.

I'd like to audio-record our conversation so I don't miss anything you want to share. Our discussion will be kept confidential and shared only with two other University of Washington researchers associated with this project. It will not affect your care by DaVita or your relationship with any of your health care providers. Your name and other identifying information will not be used.

I have a few questions in mind to get us started, but please feel free to share as much as you like. You are the expert on your care, so if there is anything you think I should know please tell me.

Do you have any questions before we get started?

1. Can you tell me why you are on dialysis?

1a. When you were diagnosed? What led you to develop kidney failure?

1b. When did you first start to see a nephrologist?

1c. FDOD? What was starting dialysis like for you? How did you incorporate it into your life?

1d. Do you have any other medical conditions that you take medications for?

2. What kinds of medications do you take on a regular basis to help you manage your medical conditions?

2a. How many pills would you estimate that you take per day?

2b. Do any of your medications have side effects?

[If yes] Can you tell me about how [medication pt identifies] affects you?

2c. Do you ever have trouble filling any of your prescriptions?

[If yes] Can you tell me more about that?

[For all] What kind of prescription insurance do you have? Has the cost of a medication ever stopped you from taking it or taking it properly?

3. Can you describe for me what a typical day is like for you when you have to come to dialysis? Let's start from the beginning, when you wake up and end with when you go to bed.

3a. Can you tell me about when you take medications during the day?

3b. Sometimes the timing of medications is a very important part of taking them properly. Do you take any medications that require you to be careful about timing? What are they called and what do they do?

4. How might a non-dialysis day be different in terms of your daily routine?

5. Are there ever times when you are not able to take all of your medications or not able to take them the way you're supposed to, such as taking them late or taking the wrong dosage?

If the answer to 5 is "yes," go to question 6. If the answer is no, go to question 7.

6. Could you tell me more about what challenges keep you from taking your [medication name here] the way your doctor would like you to?

6a. Why did your doctor prescribe [medication name here]? What benefit do you get from taking it?

6b. Is [the reason and/or benefit patient identifies] something that is important to you?

6c. How do you balance [the reason or benefit pt identifies] with [other priorities pt has identified and/or tasks in daily routine from question 3 or 4]?

**6d. How likely is it that [the reason and/or benefit patient identifies] might happen to you? Why do you think that is?**

6e. Is [the reason and/or benefit patient identifies] something you worry about?

6f. Are there any other reasons or benefits to taking [medication name here]? **If patient identifies other reasons or benefits, repeat questions 6b and 6c.**

6g. If you could change anything about taking [medication name here] so that you could take it properly, what would you change? How would that help?

7. That's very good! Why do you think you've been successful in remembering all of your medications?

7a. How do you remember to take [the medications patient identified in question 3] at the right time?

7b. Why did your doctor prescribe [the medication patient identified in question 3]? What benefit do you get from taking it?

7c. Is [the reason and/or benefit patient identifies] something that is important to you?

7d. How do you balance [the reason or benefit pt identifies] with [other priorities pt has identified and/or tasks in daily routine from question 3 or 4]?

**7e. How likely is it that [the reason and/or benefit patient identifies] might happen to you? Why do you think that is?**

7f. Is [the reason and/or benefit patient identifies] something you worry about?

7g. Are there any other reasons or benefits to taking [medication name here]? **If patient identifies other reasons or benefits, repeat questions 6b and 6c.**

7h. If you could change anything about taking any of your medications that would make them even easier to take properly, what would you change? How would that help?

8. Are there some medications that are more important to you than others? If so, which ones? Why?

9. Are there any medications that you wish you could get rid of altogether?

9a. How would your life be different if you didn't have to take [the medication they identify]?

10. Does anybody help you manage your medications at home?

11. Have you ever thought about making changes to your medication routine? If so, what kind of changes would you make?

12. Have you ever talked to a member of your dialysis team about taking medications?

11a. [If yes] What was that conversation like? **(Ask clarifying questions if needed to determine what health outcome the provider communicated to the patient)** Did you think about or make the changes he/she recommended? (Ask clarifying questions if needed to determine what the patient felt about the risk they were incurring by not making changes).

12. Do you have any plans to talk to your doctor about your medication routine? What would you want your doctor to change?

13. I've learned a lot from our discussion today. Thank you for sharing your insights with me. Is there anything else that you feel would be important for me to know?

#### Demographic questions

1. Age

2. Gender

3. Race/ethnicity

4. First date of dialysis

5. Binder prescription (type, dosage)

6. Highest grade level completed

7. Occupation

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CONSENT FORM  
Kidney Disease and Medication Management

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**Researchers' statement**

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called "informed consent." We will give you a copy of this form for your records.

**PURPOSE OF THE STUDY**

The purpose of this research study is to learn about your experience with kidney disease and medication management. Your experience as a dialysis patient is very valuable. It can help providers understand the challenges patients face with taking medications so that they can develop tools and techniques to help patients manage these challenges.

**STUDY PROCEDURES**

The study consists of one interview with a researcher. The interview is expected to last 60 to 90 minutes and can be completed chair-side during your treatment, in a private office, or over the telephone.

Examples of some questions you might be asked include:

- What kinds of medications do you take on a regular basis to help you manage your medical conditions?
- Are there ever times when you are not able to take all of your medications or not able to take them the way you're supposed to, such as taking them late or taking the wrong dosage?

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- If you could change anything about taking any of your medications that would make them even easier to take properly, what would you change?

You may refuse to answer any question during the interview.

### **RISKS, STRESS, OR DISCOMFORT**

There is a small risk of invasion of privacy since you will be asked about your day-to-day activities at home. You may share as much as they feel comfortable and may refuse to answer any questions you are not comfortable with. There is also a small risk of emotional distress as we may be talking about sensitive issues such as health care concerns and challenges you face as a dialysis patient. If needed, you may discuss your emotional concerns with your clinic's social worker or your nephrologist.

There is a risk of breach of privacy. Precautions are taken to protect your privacy at all times. Written and recorded information will not be linked or related to any personal identifiers. Any personal information given during the study will be destroyed immediately after the interview.

### **BENEFITS OF THE STUDY**

There are no material benefits to participating in this study. However, you may feel positively about participating since your experiences can be of assistance to other patients on dialysis. Information gathered in this study can assist health care providers in identifying challenges that people on dialysis face in taking medications and in developing solutions to those challenges.

### **CONFIDENTIALITY OF RESEARCH INFORMATION**

All of the information you provide will be confidential. However, if we learn that you intend to harm yourself or others, we must report that to the authorities. If you choose to be interviewed over the phone, your name and phone number will be collected. This personal identifying information will be securely destroyed immediately after completion of the interview. The study will be audio-recorded. Personal identifying information will not be collected in the audio recording. Direct quotes from audio-recordings may be used in a future publication. If used, there will be no identifying information associated with the quote.

### **OTHER INFORMATION**

You may refuse to participate and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled. This study will not produce any out-of-pocket costs to you as the participant.

### **COMPENSATION FOR INJURY**

If you think you have an injury or illness related to this study, contact the study staff Liza Orengo right away at 206-552-0646. She will treat you or refer you for treatment.

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Printed name of study staff obtaining consent      Signature      Date

Subject's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I will receive a copy of this consent form.

---

Printed name of subject      Signature of subject      Date

Copies to:      Researcher  
                         Subject

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Opt-In Form

Please read the statements below and fill in the blank spaces. Then sign and date at the bottom.

I, \_\_\_\_\_, choose to participate in the Kidney Disease and Medication Management study being conducted in my dialysis unit. I would like to be interviewed (please circle one) during treatment/in a private office/via telephone.

\_\_\_\_\_  
Printed name

\_\_\_\_\_  
Signed name

\_\_\_\_\_  
Date

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Liza Orengo  
Dietitian Script

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Human Subjects Division

NOV 21 2013

UW

Hello \_\_\_\_\_  
Patient Name

Our clinic is working with a Masters Degree student from the University of Washington. Her name is Liza. She is doing her final research project on the medications that dialysis patients take and how they affect young adults.

She would like to interview some of our patients for her final project. I think she could learn a lot from you. Would it be okay if she comes by to give you information about her project and you can decide if you would like to participate?

If yes:

Is it ok for her to meet with you during treatment or would you prefer that she call you at home? (if patient prefers phone call, please ask for best number to reach them). \_\_\_\_\_

If no:

Is it ok for me to give you a letter she wrote about the project? If you change your mind, you can contact her directly.

Thank you. She'll be in touch shortly.

OR

I understand if you prefer not to be interviewed. Please let me know if you change your mind. Thank you.

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FEB 26 2014

Dear \_\_\_\_\_ (subject name)

**UW**

Thank you for participating in today's interview. The purpose of this study was to learn about your experience managing your medications. We were especially interested in learning about how you manage your phosphate binder medications and how this is related to your understanding of health risks associated with high phosphorus.

We could not ask about phosphate binders directly because this could bias how patients respond in the interview. By withholding this information, we hoped to get the most honest and complete answers to our questions. If you have any questions about our survey please feel free to call 206-552-0646.

Thank you,

Liza Orengo  
MPH candidate  
University of Washington

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**MAR 04 2014**

UW Human Subjects  
Review Committee

## Medication Adherence in Young Adult Hemodialysis Patients

- This is a descriptive study that will explore patients' perceived susceptibility to an adverse cardiovascular event, such as stroke or heart attack, and how that relates to medication taking behaviors.
- This study is also designed to explore the barriers to optimal medication adherence in young adult patients on hemodialysis.

### Thesis

**W**  
UNIVERSITY of  
WASHINGTON

*DaVita*  
Clinical Research.

This project has been approved by the Human Subjects Division of the University of Washington and DaVita Clinical Research. The medical director of each unit has provided written consent to proceed as have the Regional Operations Directors of both Region I and Region IV.

### Study Approval

- Tacoma
- Federal Way
- Olympia
- Lakewood
- Olympic View
- Mill Creek
- Westwood

### Clinics Approved for Study

- 1) Patient on hemodialysis > 90 days prior to the start of the study
- 2) Between the age of 18-44 years old,
- 3) Oriented to person, place, and time,
- 4) Speaks English, and
- 5) The patient is prescribed a phosphorus binder to take with meals.

### Patient Eligibility Criteria

- One interview session per patient
  - Chair-side, in conference room, or via telephone
- Audio-recorded
- No patient identifiers used
- Confidential; information will not be shared with anyone outside of research team.
- No compensation or incentives offered
- Patient will have to sign consent form prior to participating

### Study Design

- Identify patients in your clinic who meet criteria
- Approach patients about participating using an approved script
- Post a recruitment flyer in your clinic's lobby
- When approaching patients or discussing the project, please identify me as a **Masters student only**. Identifying me as a DaVita employee and/ or Dietitian could introduce bias.

## Request of Fellow Dietitians

Hello \_\_\_\_\_  
Patient Name:

Our clinic is working with a Masters Degree student from the University of Washington. Her name is Liza. She is doing her final research project on the medications that dialysis patients take and how they affect young adults. She would like to interview some of our patients for her final project. Would it be okay if she comes by to give you information about her project and you can decide if you would like to participate?

If yes:

Is it ok for her to meet with you during treatment or would you prefer that she call you at home? (If patient prefers phone call, please ask for best number to reach them). \_\_\_\_\_

If no:

Is it ok for me to give you a letter she wrote about the project? If you change your mind, you can contact her directly.

Thank you. She'll be in touch shortly.

OR

I understand if you prefer not to be interviewed. Please let me know if you change your mind. Thank you.

A STAMPED version of this form is being faxed to your centers.

## RD Recruitment Script

- A student from the University of Washington is conducting a study on kidney disease and medication management. If you are a hemodialysis patient between the ages of 18-44 you may be eligible to participate. Subjects will be asked to complete one interview session with a researcher. Your experiences are very valuable and can help other dialysis patients! If interested, please call Liza at 206-552-0646.
- Please hang the STAMPED version of this form (it is being faxed to your centers).

## Recruitment Flyer

- Please email or call me to let me know of any interested patients. I can be reached at any of the following:
  - E: [lorengo@uw.edu](mailto:lorengo@uw.edu) or [liza.orengo@davita.com](mailto:liza.orengo@davita.com)
  - P: 206-552-0646
  - F: 1-866-319-2394
- I will follow up at their next Friday or Saturday treatment to answer any questions and obtain signature on opt-in form.
- If patient permits, I will interview them that day as well, or we can schedule a time for the interview.

## Next Step