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# Development and Evaluation of a Peer-to-Peer Intervention to Increase Self-Management among Adult In-Center Hemodialysis Patients

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**Development and Evaluation of a Peer-to-Peer Intervention to Increase Self-Management among  
Adult In-Center Hemodialysis Patients**

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University

by

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## Table of Contents

List of Tables	vi
List of Figures	vii
Abstract	viii
Chapter 1 Introduction and Specific Aims	1
Specific Aims	3
Chapter 2 Literature Review and Formative Work	6
Self-Management in Chronic Disease	6
Self-Management in Hemodialysis	7
Follow Prescribed Treatment Regimen	8
Adhere to Diet and Fluid Restriction	9
Take Medications as Prescribed	9
Obtain and Maintain Vascular Access	10
Non-Adherence and Its Consequences	11
Peer Mentoring as an Intervention for Chronic Disease Management	12
Peer Mentoring as an Intervention among Patients with Kidney Failure	13
Peer Mentoring in Other Chronic Conditions	15
Limitations in the Existing Literature	18
Theoretical Framework	19
Social Cognitive Theory	19
Psychosocial Constructs to Improve Self-Management	21
Social Support	21
Knowledge	22
Self-Efficacy	23
Mechanisms of Change	25
Summary	25
Chapter 3 Methods	28
Study Site	28
Intervention and Evaluation Overview	30
Peer Mentoring Intervention	31
Participant Eligibility	31
Participant Recruitment	32
Mentor Training	35
Mentee/Mentor Pairing	36
Program Launch/Social Mixers	37
Mentor/Mentee Interaction	38
Mentor Training Boosters	39
Final Celebration Mixer	39

Evaluation of the Intervention	41
Power Calculation	41
Aim 1	42
Data Collection	42
Data Analysis	43
Aim 2	44
Data Collection	44
Data Analysis	49
Aim 3	51
Data Collection	51
Data Analysis	51
Data Management	51
Chapter 4 Results	52
Aim 1	52
Recruitment, Participation, and Attrition	52
Mentor Training	54
Mentor/Mentee Interaction	55
Overall Participant Satisfaction	56
Staff Perceptions and Facility Resources	56
Aim 2	68
Aim 3	69
Chapter 5 Discussion	71
Effects of Peer Mentoring on Mentees	71
Effects of Peer Mentoring on Mentors	74
Considerations for Implementation	75
Patient Participation	75
Identifying Mentors	76
Training Mentors	77
Pairing Mentors and Mentees	79
Dialysis Facility and Staff Roles	82
Areas for Additional Inquiry	83
Length of Time on Dialysis and Health-Related Quality of Life	83
Marital Status and Perceived Social Support	84
Limitations/Threats to Validity	86
Small Sample Size and Post Hoc Analyses	86
Selection Bias	87
Response Bias	87
Maturation Bias	88
Attrition	88
Chapter 6 Conclusion	90
Bibliography	91

Appendices	102
Appendix A Environmental Scan within Dialysis Community	102
Appendix B Formative Research at UVA Lynchburg Dialysis	116
Appendix C Participant Application	123
Appendix D Recruitment Flyer	125
Appendix E Recruitment Brochure	126
Appendix F Facility Staff Patient Nomination Form	130
Appendix G Sample Agenda for Mentor Training	132
Appendix H Mentor Communication Skills and Role-Play Observation Form	134
Appendix I Mentor Training Evaluation Form	136
Appendix J Participant Confidentiality Form	139
Appendix K Meeting Log	140
Appendix L Participant Consent	142
Appendix M University of Virginia IRB Determination	146
Appendix N Virginia Commonwealth University IRB Determination	147
Appendix O Participant Satisfaction (Mentor)	148
Appendix P Participant Satisfaction (Mentee)	151
Appendix Q Participant Survey	154
Vita	168

## List of Tables

1: Non-Adherence Rates in Hemodialysis	8
2: Demographics of UVA Lynchburg Dialysis Patients as Compared to U.S. Patients by Treatment Modality	29
3: Study Timeline	44
4: Survey Timeline by Role	45
5: Outcome Variables	46
6: Age by Role	58
7: Years Receiving ESRD Treatment	58
8: Demographic Characteristics of <i>Peer Up!</i> Participants	59
9: Mentor Training: Overall Feedback	60
10: Mentor Training: Self-Reported Confidence Level by Task	61
11: <i>Peer Up!</i> Meeting Log Summary	62
12: Mentee Program Evaluation	64
13: Mentor Program Evaluation	65
14: Staff Survey: Impact on Job	66
15: Staff Perceptions of Patient Benefits	67
16: Staff and Facility Resources Required	67
17: Comparison of Psychosocial Measures across Time Periods, Mentees	68
18: Comparison of Psychosocial Measures across Time Periods, Mentors	70
19: Comparison of Health-Related Quality of Life by Time on Dialysis, Mentees	84
20: Comparison of Perceived Social Support by Marriage, Mentees	85
21: Comparison of Perceived Social Support by Marriage, Mentors	86



## List of Figures

1: Heisler's Hypothesized Model of Peer Support	13
2: Types of Health Behavior Theory	20
3: Social Cognitive Theory: Triadic Reciprocal Causation	20
4: Conceptual Model	21
5: Logic Model of Peer-to-Peer Program	40
6: Mentee C and Mentor S	62
7: Mentee R and Mentor G	62
8: Overall Participant Experience	63
9: Participant Quotes from Survey	63
10: Staff Quotes from Survey	66
11: Intention to obtain an AVF or AVG	69
12: Mentee G and Mentor B	69

## **Abstract**

### **DEVELOPMENT AND EVALUATION OF A PEER-TO-PEER INTERVENTION TO INCREASE SELF-MANAGEMENT AMONG ADULT IN-CENTER HEMODIALYSIS PATIENTS**

By Jennifer J. St. Clair Russell, Ph.D.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2016

Advisor: Maria Thomson, Ph.D., Assistant Professor, Department of Health Behavior and Policy

**Background:** Peer-to-peer (P2P) support programs have the potential to assist ESRD patients in managing their disease and improve outcomes. Yet, there is little research examining P2P programs' impact on psychosocial outcomes and disease management behaviors.

**Methods:** A 4-month P2P mentoring intervention was designed and piloted in a facility serving 249 in-center hemodialysis patients in Lynchburg, Virginia. Preceded by a social marketing effort, which included a program naming contest and participant recruitment, the intervention included: (1) mentor training, (2) pairing of mentees and mentors, (3) kick-off social mixers, (4) ongoing meetings between mentees and mentors, (5) mentor training booster, and (6) a final celebration.

A single arm quasi-experimental study with repeated measurements at three time points was used with data collection over four months. The hypotheses that the intervention would

result in improvements for both mentees and mentors (i.e., self-efficacy, knowledge, perceived social support, dialysis social support (i.e., support from peers within the dialysis setting), and self-management behaviors) were tested using repeated measures ANOVA or the Friedman's test for nonparametric data.

**Results:** Mentees experienced increases in self-efficacy,  $F(2,22)=8.15, p<.01$ ; knowledge,  $F(2,44)=6.62, p<.01$ ; perceived social support,  $F(2,22)=7.30, p<.01$ ; and dialysis social support,  $F(2,44)=4.79, p=.01$ . Mentors experienced increases in knowledge,  $F(2,22)=11.88, p<.01$ ; dialysis social support,  $F(2,42)=3.19, p=.05$ ; and dialysis self-management,  $\chi^2(2) = 7.65, p =.02$ .

**Conclusion:** A P2P mentoring program for in-center hemodialysis patients can be beneficial for both mentees and mentors. Future research should focus on larger groups of patients using more rigorous research designs.

## **Chapter 1 Introduction and Specific Aims**

Peer-to-peer (P2P) mentoring programs have the potential to assist patients with kidney failure in managing their complex chronic illness to improve outcomes. Despite the significant disease management and self-care burden this population faces, there is little research examining the effectiveness of P2P programs in improving psychosocial outcomes and disease management behaviors.

Chronic kidney disease (CKD) is a growing problem in the United States. More than 26 million Americans have some stage of CKD, and its prevalence is rising.<sup>1</sup> Chronic kidney disease can progress to chronic kidney failure, known as end stage renal disease (ESRD), in which some form of kidney replacement therapy (i.e., dialysis or transplantation) is required to sustain life. In 2011, 615,899 Americans received treatment for ESRD.<sup>2</sup> The two primary causes of kidney failure are diabetes and hypertension, at 44.2% and 28.6% of cases, respectively.<sup>2</sup> It is not surprising that the number of Americans with CKD is expected to rise and projected to reach 774,386 by 2020<sup>3</sup> as both diabetes and hypertension are highly prevalent in the U.S. population. The American Diabetes Association (ADA) estimates that 29.1 million children and adults (9.3% of the U.S. population) have diabetes,<sup>4</sup> and the American Heart Association (AHA) estimates that 77.9 million adults, ages 20 and older, (approximately 33% of U.S. adults) have hypertension.<sup>5</sup>

Patients with kidney failure tend to have significant comorbidities including ischemic heart disease and congestive heart failure, cerebrovascular disease, and/or peripheral vascular

disease.<sup>6,7</sup> Patients also tend to have a high symptom burden, experiencing a variety of symptoms such as anxiety, depression, pruritus, anorexia, nausea, insomnia, fatigue, and pain—often in combination.<sup>8,9</sup>

The majority of patients with kidney failure are treated by in-center hemodialysis, as opposed to home hemodialysis, peritoneal dialysis or kidney transplant, and typically require a 4-hour extracorporeal treatment three times weekly.<sup>2,10</sup> For many, in-center hemodialysis treatments are associated with significant adverse effects, including nausea, hypotension, itching, and cramping. To achieve the best outcomes, patients receiving in-center treatment must follow a complex self-management regimen and practice behaviors that promote treatment efficacy, such as monitoring fluid intake, adhering to dietary restrictions, and managing a complex medication schedule. However, research has shown that as a treatment regimen increases in complexity and length, adherence tends to decrease.<sup>11</sup> Further, the self-management of ESRD may be especially challenging because the diagnosis and functional limitations constitute such a profound physical, social, and financial loss for patients and their families. For example, many patients are unable to continue working and some require the assistance of a caregiver.<sup>12-14</sup>

Peer programs provide patients with ongoing disease self-management information, emotional support, and mutual reciprocity to achieve outcomes that include improved patient health-related quality of life, health behavior, and chronic disease control, while reducing unnecessary hospitalizations and costs.<sup>15-17</sup> Self-management support goes beyond traditional knowledge-based patient education to include processes that develop patient problem-solving skills, improve self-confidence, and support patient application of knowledge to manage their chronic disease. Research, though limited, suggests the act of helping others confers benefits to peer mentors as well, thus both mentees and mentors can benefit.<sup>18</sup> The management and

treatment of chronic disease is an ongoing challenge in health care and is certainly not unique to ESRD. Nevertheless, self-management is particularly relevant for this population because controlling diet and fluid intake plays such a crucial role in treatment and outcomes. Further, the in-center dialysis population is unique given the amount of time each week they must spend in a facility receiving treatment.

### **Specific Aims**

The primary goal of this pilot study is to evaluate the impact of a 4-month P2P program introduced in one western Virginia dialysis center on patients' psychosocial health outcomes. Specifically, the aims of this program evaluation are:

**Aim 1:** To evaluate the implementation of a P2P program for dialysis patients.

**RQ#1:** How many patients volunteer as mentors?

**RQ#2:** How many patients seek to participate as mentees?

**RQ#3:** How many patients complete the training to serve as a mentor?

**RQ#4:** What are the mentors' perceptions of the mentor training?

**RQ#5:** How many mentors complete at least one interaction with a mentee?

**RQ#6:** How many P2P interactions are logged during the intervention period?

**RQ#7:** How many mentees complete the 4-month program?

**RQ#8:** How many mentors complete the 4-month program?

**RQ#9:** What center and staff resources are required and desired to support the 4-month P2P program?

**RQ#10:** What are mentors and mentees perceptions of the 4-month program (e.g., pros, cons, satisfaction)?

**Aim 2:** To evaluate the impact of a 4-month P2P program on patient mentees'

knowledge, psychosocial health indicators (i.e., self-efficacy, perceived social support,

and dialysis social support), and dialysis self-management behaviors as assessed via paper/pencil survey. Using a quasi-experimental, single-center longitudinal design, with assessments at three time points (pre-intervention (Month 0), mid-intervention (Month 2), and post-intervention (Month 4)) and patient mentees serving as their own controls, it is hypothesized that after participation in the P2P program mentees will:

**H1:** Demonstrate increased self-efficacy, knowledge, perceived social support, and dialysis social support, as compared to baseline measures.

**H2:** Report greater intent to consult with a vascular surgeon regarding the placement of an arteriovenous fistula (AVF) vascular access (*patients with a central venous catheter (CVC) only*), as compared to baseline measures.

**H3:** Report increased frequency of dialysis self-management behaviors (i.e., coming to dialysis treatment the prescribed number of times per week, completing the full treatment time each treatment, adhering to prescribed diet, following fluid restrictions, taking all medicines, and taking medicines on a set schedule) as compared to baseline measures.

**Aim 3:** To evaluate the impact of a 4-month P2P program on patient mentors' knowledge, psychosocial health indicators (i.e., self-efficacy, perceived social support, and dialysis social support), and dialysis self-management behaviors as assessed via paper/pencil survey. Using a quasi-experimental, single-center longitudinal design, with assessments at three time points (i.e., pre-training (Month 0), post-training/pre-intervention (Month 0), and post-intervention (Month 4) and mentors serving as their own controls, it is hypothesized that after participation in the P2P program mentors will:

**H4:** Demonstrate increased self-efficacy, knowledge, perceived social support, and dialysis social support, as compared to baseline measures.

**H5:** Maintain self-reported frequency of dialysis self-management behaviors (i.e., coming to dialysis treatment the prescribed number of times per week, completing the full treatment time each treatment, adhering to prescribed diet, following fluid restrictions, taking all medicines, and taking medicines on a set schedule), as compared to baseline measures.



## **Chapter 2 Literature Review and Formative Work**

Patients receiving in-center hemodialysis for treatment of kidney failure face tremendous self-management challenges. Peer mentoring may positively impact their adherence to their self-care regimen and ultimately improve medical outcomes. This chapter will describe self-management in the context of chronic disease as well as the self-management tasks in-center hemodialysis patients face and why adherence is such a challenge. Further, it will explore how peer mentoring has been used specifically among patients with kidney disease and its use in other chronic diseases, such as diabetes and heart failure. This review helps to better understand how peer mentoring has been implemented and identify lessons that may inform the development and testing of a peer mentoring intervention specifically designed for in-center hemodialysis patients. This chapter will conclude with a discussion of the behavioral constructs of interest, self-efficacy, knowledge, and perceived social support, as supported by Social Cognitive Theory and the extant disease self-management literature.

### **Self-Management in Chronic Disease**

Chronic diseases require ongoing care to mitigate symptoms while maximizing functioning as no cure exists.<sup>19,20</sup> In most cases, it is not reasonable or feasible, financially or otherwise, to administer such care in an acute or long-term care setting; therefore, much of the care tasks must be done by the patient via self-care or self-management techniques.<sup>21-24</sup> Self-management has been defined as: “The positive efforts of patients to oversee and participate in their health care in order to optimize health, prevent complications, control symptoms, marshal

medical resources, and minimize the intrusion of the disease into their preferred lifestyle.”<sup>25,26</sup>

Self-management is sometimes used in conjunction with adherence, which the World Health Organization has defined as: “The extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.”<sup>27</sup>

Self-management in chronic disease has been shown to improve outcomes, including overall health status and sense of well-being while reducing hospitalization.<sup>16,28,29</sup> Self-management plays an integral role in health care. Arguably, it can increase quality of life for patients and reduce costs for payers; however, the self-management tasks are not always easy and patients may not always have the resources they need to adhere to their complex treatment regimen.

### **Self-Management in Hemodialysis**

The kidneys play an integral role in body processes. They eliminate toxins, waste, and excess fluid from the body, control blood pressure, keep bones healthy, and generate red blood cells. When the kidneys stop working, in-center hemodialysis can replace the natural function of the kidneys, but it cannot accomplish the same outcomes in 12 hours per week (e.g., three treatments of four hours each week) that the kidneys were doing around the clock.<sup>10</sup> Therefore, it is necessary for patients to perform self-management tasks and adhere to their treatment regimen in order to optimize dialysis treatment and stay alive. The recommendations typically associated with dialysis include following the prescribed treatment regimen (i.e., attending all dialysis treatments and completing the number of prescribed minutes per treatment) as well as adhering to a special diet and fluid limitations, and taking medications as prescribed.<sup>30</sup> Estimations of the non-adherence rates to these recommendations tend to vary from 7.9% - 50% across the extant literature (Table 1). Seeking placement of a vascular access and maintaining it is another

recommendation, but only 23.2% of incident hemodialysis patients have an arteriovenous fistula or graft at month four (day 91) of treatment.<sup>2</sup> It is clear that hemodialysis patients tend to struggle with these tasks and following their medical providers' recommendations.<sup>31,32</sup>

**Table 1: Non-Adherence Rates in Hemodialysis<sup>31,32</sup>**

<b>Behavior</b>	<b>% of Non-Adherence</b>
Missed treatments	7.9% - 8.5%
Shortened treatments (>10 minutes)	19.6% - 20.3%
Medication non-adherence	15.4% - 50.2%
Fluid non-adherence	9.7% - 49.5%
Diet non-adherence	9% - 22.1%

### **Follow Prescribed Treatment Regimen**

While all patients may miss or shorten treatment from time to time, the US ESRD population disproportionately misses or shortens treatment more frequently, as compared to Europe and Japan.<sup>33</sup> This is despite evidence that suggests skipping treatment results in higher mortality and hospitalization rates.<sup>33,34</sup> In general, in-center hemodialysis patients are recommended to attend treatment three times per week for four hours per treatment.<sup>10</sup> Thus, at a minimum, 12 hours of each week is required to be spent at an outpatient dialysis facility, not including time for traveling to and from the location or any waiting times. This regimen is to be followed as long as the patient uses in-center hemodialysis as his/her renal replacement therapy, which for some, may be the rest of his/her life. This demanding treatment schedule makes it challenging for patients to remain employed and continue their routines prior to diagnosis and treatment. Some of the reasons patients may miss or shorten appointments may be physiological (e.g., they feel poorly) or logistic (e.g., transportation issues or conflicting medical appointments). However, non-adherence can also be more psychosocially complex, for example, it has been suggested that patients who have not adjusted adequately to the diagnosis

and/or treatment regimen may begin missing or shortening treatments as “...a subtle expression of control over their health status.”<sup>33</sup>

### **Adhere to Diet and Fluid Restrictions**

The kidneys eliminate excess fluid from the body and help to clean the blood. When they are not working, patients are instructed to try to limit their fluids and eat a special diet to help limit the build-up of fluid and toxins between treatments. Typically, patients are limited to about 32 – 36 ounces of liquid per day.<sup>35,36</sup> This amount includes drinks, like coffee, tea, and water (for drinking and taking medication), but also soups, ice cream, gelatin, etc. Patients are advised to maintain a diet low in sodium, potassium, phosphorus and higher in protein.<sup>37</sup> This is further complicated if the patient also has diabetes or other co-morbid conditions that impact diet.<sup>38</sup> Patients often find the diet and fluid restrictions disorienting and intensely burdensome.<sup>38</sup> These restrictions tend to exacerbate decreased quality of life and strain relationships, including those with the medical team.<sup>38</sup>

### **Take Medications as Prescribed**

ESRD patients are estimated to take eight to twelve prescribed medications per day requiring an average of 17-25 doses per day.<sup>39,40</sup> However, some may take as many as 15-20 medications.<sup>40</sup> Medications are taken for a variety of issues and depend on the specific patient, but often include medications for anemia, bone disease and calcifications, and phosphorus management.<sup>41</sup> Medications may also be required to manage co-morbid conditions like hypertension and/or diabetes. Non-adherence to the medication regimen can result in a variety of complications and worsening of conditions, such as bone disease, anemia, cardiovascular issues, and hypertension.

## **Obtain and Maintain Vascular Access**

Obtaining an arteriovascular fistula (AVF), placed by a vascular surgeon, and maintaining it are also self-management tasks that are important to patient outcomes. An AVF is the preferred vascular access for hemodialysis because it has a lower risk of infection and provides for better blood flow, thereby reducing treatment time.<sup>42</sup> However, many patients begin dialysis with a central venous catheter (CVC) because they must start treatment immediately and CVCs do not require time to mature. Unfortunately, CVCs tend to have high infection rates which often leads to hospitalization.<sup>42,43</sup> AVFs can require as much as two to three months to mature, although this can vary.<sup>44</sup> Some patients prefer to keep their CVC and avoid pursuing an AVF for a variety of reasons. These include the belief that dialysis is only temporary and they will receive a transplant soon, they do not want to have a surgery, or they have heard that cannulation prior to each treatment is painful.<sup>45</sup> Once placed, an AVF requires some maintenance. For example, patients with an AVF in an arm should avoid heavy lifting with that arm and should try not to sleep or lay on that arm.<sup>46</sup> The AVF must also be checked periodically to make sure that the blood flow is adequate. Finally, the access site should be cleansed before each use.

## **Non-Adherence and Its Consequences**

Non-adherence or inadequate self-management in any of these tasks can have significant consequences, including hospitalization due to infections and cardiovascular issues, rehospitalization, or death.<sup>2,32,47</sup> According to the 2012 United States Renal Data System (USRDS),<sup>48</sup> patients on dialysis were hospitalized more frequently than the general Medicare population, with adjusted rates of 1.88 per year and 0.6, respectively. The all-cause adjusted hospitalization rates per patient have shown little change over the last decade in hemodialysis.<sup>2</sup>

The highest rates of hospitalization (overall and cause-specific diagnoses) are among those age 20-44 or 75 and older, female, white, black/African American, or have diabetes as the primary diagnosis for their kidney failure.<sup>2</sup> Rehospitalization (i.e., a hospital admission within 30 days of a live discharge) is also a significant problem for the ESRD population with the overall rate at approximately 33%, which is 70% higher rate than the general Medicare population.<sup>2,39</sup>

Non-adherence to each of these self-management tasks have associated risks independently. For example, patients who are not limiting their fluids are at risk for fluid overload. Fluid overload can cause a number of adverse effects, including coughing, edema, shortness of breath, chest pain, and congestive heart failure. Further, there is a limit to the amount of fluid that can be safely removed in one treatment. Removing higher volumes of fluid during treatment can put patients at risk of serious side effects, such as hypotension, cramping, nausea, headache, and cardiac complications (e.g., ischemia–reduced blood flow to the heart and lasting heart damage), or death.<sup>36,49-51</sup> However, non-adherence to one task may have a snowball effect and cause other problems. For instance, missing or shortening a treatment can increase the likelihood of fluid overload and a patient experiencing the associated adverse effects. Similarly, serum phosphorus level is impacted by missed or shortened treatments, but also by diet and medication regimen. Many dialysis patients are prescribed phosphate binders, a medication to help manage phosphorus. Not taking medication, such as phosphate binders, as prescribed on a regular schedule can lead to problems such as increased bone fractures, pruritus, heart issues, and calcification and hardening of tissues.<sup>52</sup>

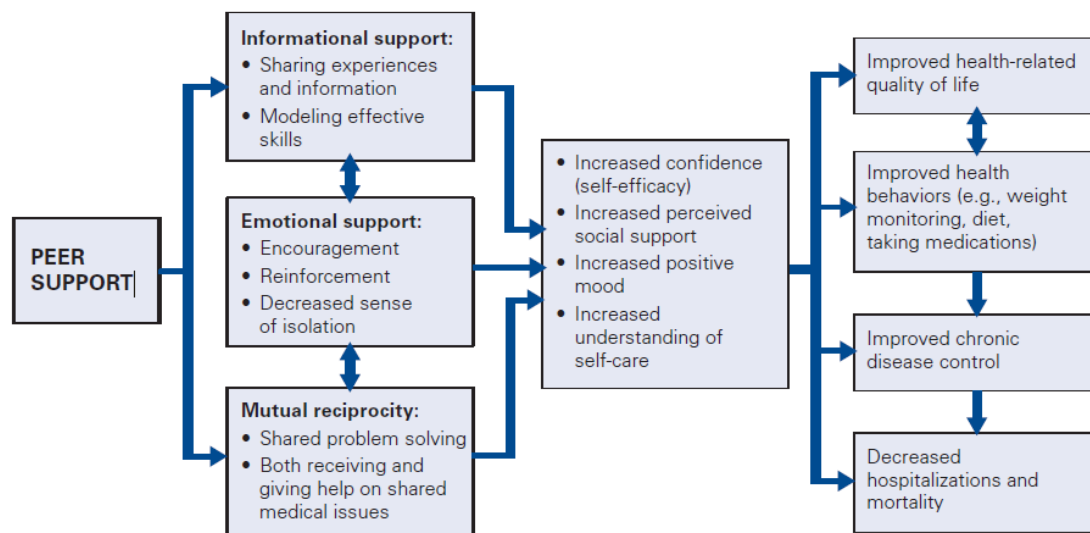
It is evident that hemodialysis patients have a significant self-care burden and non-adherence can result in significant morbidity, hospitalization, and death. While health professionals may do their best to educate and prepare patients for this new lifestyle, experiences

of fellow patients can provide an invaluable informal source of patient information and support. There is evidence to suggest that this informal support can influence fellow patients' behavior and health care decisions, and in some cases, have more influence than advice provided by physicians.<sup>53,54</sup> Experienced patients building a relationship and sharing their stories with other patients, such as those who are new to dialysis or those who are struggling with adherence, can help reinforce positive behaviors and improve behaviors that may be lacking. Further, some peer support may already occur organically within the waiting areas of dialysis facilities because some patients have a desire to share their stories with others. Individuals want to share their experiences with other patients to help improve their quality of life, help others learn from their mistakes, or assist others' adoption to new treatment regimens.<sup>38</sup> A formalized support program, like a peer mentoring program, can expand what may be occurring organically, provide patients with an outlet to share their experiences, and potentially improve outcomes.

### **Peer Mentoring as an Intervention for Chronic Disease Management**

It is hypothesized that peer support via various mechanisms (i.e., informational support, emotional support, and mutual reciprocity) can lead to a variety of beneficial outcomes, including improved health behaviors, quality of life, improved chronic disease control, and decreased hospitalization (Figure 1).<sup>15</sup> Heisler has proposed a typology categorizing peer support models into the following seven categories: professional-led group visits with peer exchange; peer-led, face-to-face self-management programs; peer coaches; community health workers; support groups; telephone-based peer support; and web- and email-based programs.<sup>15</sup> Peer coaching, also referred to as peer mentoring, is defined as "...meet[ing] one-on-one with other patients to listen, discuss concerns and provide support." It can provide patients with individualized information, alleviate fears, and help patients adapt to their diagnosis.<sup>15,55</sup> Inherent in peer mentoring

relationships is the ongoing support that occurs as the result of multiple meetings or interactions. Patients receiving in-center dialysis treatment are uniquely positioned to benefit from peer mentoring given that they spend so much time together receiving treatment. Further, the most plentiful yet untapped resource at a dialysis facility is the patients themselves. They spend a great deal of time at the dialysis facility each week, not only receiving treatment, but also waiting for transportation, and that time could be used to support each other.



**Figure 1: Heisler’s Hypothesized Model of Peer Support<sup>15</sup>**

**Peer Mentoring as an Intervention among Patients with Kidney Failure**

Limited evidence exists in the extant literature related to increasing self-management within ESRD through peer mentoring. Of the three studies identified, two based in the US and one in the UK, none specifically focused on in-center hemodialysis patients and increasing self-management. Walker et al. examined how post-transplant patients serving as peer mentors in a hospital-based program may affect time to being listed on the transplant list and self-reported quality of life among patients.<sup>56</sup> No significant differences were found between those who had a peer mentor and those who did not with either outcome. Conversely, the qualitative study



conducted by Hughes et al. sought to explore patients' experiences receiving peer support, specifically among patients transitioning to dialysis in the UK.<sup>57</sup> Their findings indicated that patients found peer-to-peer interaction helpful, with 90% reporting that they found it to be a positive experience. Lastly, the three-arm randomized control trial conducted by Perry et al. in 21 dialysis centers in Michigan explored how peer mentors might assist with end-of-life decision making and the completion of advance directives (AD).<sup>58</sup> The arms consisted of usual care, receipt of written material about advance care planning, or peer mentoring. Peer mentoring showed significant differences compared to the other groups, specifically related to the completion of ADs, the desire to complete ADs, and comfort discussing ADs. The influence of peer mentors appeared to be most prominent among African American patients and the authors' conjecture that this due to cultural differences. Based on these conflicting findings, more research is needed with in-center hemodialysis patients specifically focusing on dialysis self-management behaviors.

Due to the lack of substantial evidence focusing on peer mentoring to improve self-management among in-center hemodialysis patients, an environmental scan was conducted in summer 2014 to determine what peer mentoring programs existed in the field, but have not been formally evaluated and/or do not have results published in the extant literature. An online survey, consisting of approximately 18 questions, was developed to identify individuals (e.g., professionals and patients) who may have experience with any type of peer programs in the U.S. ESRD community. Thirty-one peer programs were identified from 452 survey respondents. Staff or patients representing peer programs submitted were contacted for interviews. Interviews were held with 23 individuals. The interviews elicited information about the program's structure, goals, audience, mentor training, and evaluation. Five formal peer mentoring programs were identified.

These generally focused on increasing patient engagement in their own care, and improving dialysis self-management behaviors, education, and support. One program completed a randomized controlled trial to evaluate its effects. This research was identified in the extant literature and summarized earlier in this chapter (Perry et al.). Another program was beginning a formal evaluation at the time of the interview while the remaining programs had not been formally evaluated, but were collecting some data to support informal program impact assessments. None of the programs were guided by a specific theoretical foundation; however, program descriptions often focused on developing patients' self-efficacy or confidence with self-management tasks. The common characteristics that emerged were active involvement of patients, or even being completely patient-led, was critical to sustainability; training of mentors was essential to provide information related to kidney failure as well as to emphasize privacy and confidentiality; and working closely with the dialysis center staff and having buy-in from the medical director is absolutely necessary from the start of the program. Thus, any peer mentoring program for in-center dialysis patients must meet patients' needs, while working within the constraints of available resources and organizational policies. For a full description of the methods and results of the environmental scan, refer to Appendix A.

### **Peer Mentoring in Other Chronic Conditions**

Although limited research has focused on the use of peer mentoring to increase self-management within ESRD, a robust peer mentoring literature exists for other chronic conditions including diabetes, heart failure, and arthritis. This literature can provide insights into what types of peer mentoring interventions may be successful with in-center hemodialysis patients. As one of the leading causes of kidney failure, the literature pertaining to peer mentoring to increase self-management among patients with diabetes is particularly salient. Many dialysis

patients are also managing diabetes.<sup>2</sup> Further, diabetes self-management requires similar practices as kidney failure, including diet modification, self-monitoring of health status, and adherence to a medication regimen.<sup>59,60</sup>

Within the diabetes literature, psychosocial measures (i.e., self-efficacy, knowledge, and social support) were considered secondary outcomes, if reported. Some studies did not report any findings related to these constructs. The majority of studies focused primarily on a specific clinical outcome, hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>), which is a measure of glycemic control. The HbA<sub>1c</sub> blood test provides the average level of blood glucose during the last three months and is the primary test used in clinical practice to determine how well the condition has been managed.<sup>61</sup> Three randomized controlled trials (RCT) and one non-randomized controlled trial were identified, each with intervention periods of six months. All three RCTs indicated that face-to-face peer mentoring significantly decreased HbA<sub>1c</sub>. The study conducted by Heisler et al. with 244 men in two Veterans Affairs health care facilities indicated that peer mentoring was helpful in significantly reducing HbA<sub>1c</sub> as compared to care provided by nurse care managers.<sup>62</sup> They also found that peer mentoring had a significant improvement in one of their secondary outcomes, diabetes social support. Long et al. reported similar findings in her 3-arm study conducted with 118 African American Veterans.<sup>63</sup> Compared to usual care and a group receiving financial incentives to decrease their HbA<sub>1c</sub>, peer mentoring showed the greatest reduction in HbA<sub>1c</sub>. Finally, Thom et al. found that peer mentoring significantly improved diabetes control among low-income, underserved patients in six public health clinics in San Francisco when compared to those receiving usual care.<sup>64</sup> Conversely, the non-randomized controlled trial conducted by Knox et al. in 15 primary care practices in San Antonio, Texas found that both those receiving usual care and those participating in a peer mentoring relationship demonstrated decreases in their

HbA<sub>1c</sub>.<sup>65</sup> This was presumed to be related to the setting that the intervention was used in, which is described as offering “...well-organized comprehensive diabetes care...” and contributed to low baseline HbA<sub>1c</sub> values and well-controlled diabetes prior to the intervention. However, self-management behaviors significantly improved from baseline to 6-month follow up among those in the intervention group. These participants also reported less social isolation and demonstrated significant improvements in diabetes knowledge.

While not as well examined as peer mentoring in diabetes, peer mentoring has shown promising results in patients with heart failure. In a 3-month RCT, the intervention group reported significantly more self-care behaviors and higher self-care self-confidence than those in the usual care group; however, no differences were observed in hospital readmissions, length of stay, or cost.<sup>66</sup> Though not statistically significant, the intervention group had a 96% higher readmission rate when compared to the usual care group and the authors hypothesize that this was due to seeking care earlier due to heightened symptom recognition.

Peer mentoring has also been used with patients to manage early inflammatory arthritis; however, it appears that evaluation of peer mentoring in this chronic disease is in its infancy as only one feasibility and pilot study was identified with nine dyads (i.e., one mentor and one mentee each) over a 12-week intervention period.<sup>67</sup> Nevertheless, the findings were promising in that mentees reported increased health-related quality of life, ability to cope, and social support via surveys. This study, though limited due to its small sample, was one of the only ones to explore the impact of mentoring on mentors and those results were mixed. During interviews, mentors stated that they benefited from the program as well in that it increased their knowledge, presented them with additional coping strategies and self-management techniques, while reinforcing what they already knew. Mentors also realized and appreciated how much progress in

coping and self-management they had made since their own diagnosis and disease course. However, the mentor training appeared to have a more positive impact on self-efficacy than did the interactions with their mentee. Mentor self-efficacy increased immediately following training, but decreased throughout the course of the intervention and at 3-month post-intervention. This is concerning as it may indicate that mentoring may be difficult and stressful leading to adverse effects for mentors. Finally, a RCT conducted with patients with a variety of chronic diseases (i.e., arthritis, asthma, chronic obstructive pulmonary disease, congestive heart failure, depression, and/or diabetes) found that there were increases in mentee self-efficacy during the program, but those increases waned overtime and were no longer significant 1-year post-intervention.<sup>68</sup> The interactions took place in the homes of the mentees and attempted to pair dyads based on personality factors.

### **Limitations in the Existing Literature**

The results in the limited ESRD-focused research have been mixed and have not focused specifically on self-management. Peer mentoring programs exist in the community but have not been thoroughly evaluated due to resource restrictions, including staff, time, and money. The majority of literature examining the effects of peer mentoring on chronic disease self-management focuses on diabetes. While the results have been promising, the primary outcome of interest was HbA<sub>1c</sub> with limited discussion or reporting of the psychosocial elements, such as self-efficacy and social support. Perhaps this is because objective clinical measures exist that can be applied in that particular disease or, based in the health behavior theory, it is assumed that these psychosocial outcomes and knowledge must be impacted in order to affect behavior change and ultimately clinical outcomes. Regardless, the knowledge of the mechanisms of change is limited. It is not known why these particular interventions were effective or what the key

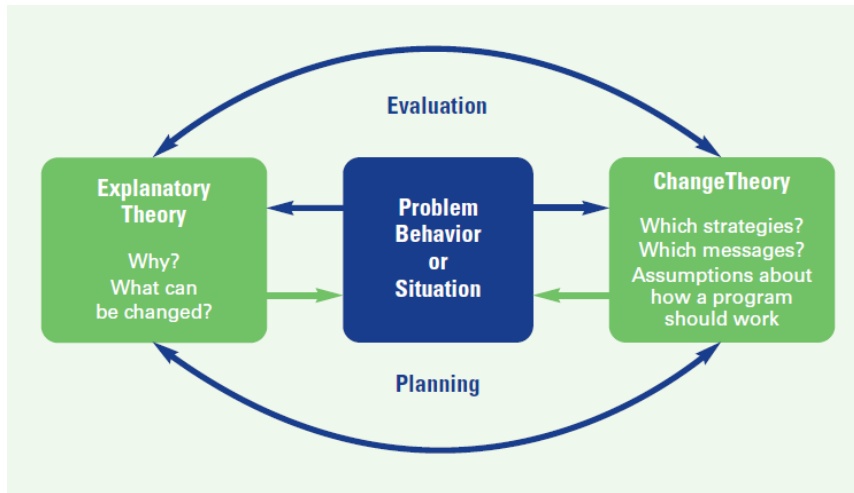
elements were that would need to be replicated to translate the findings into recommendations. This limits the ability to develop evidence-based practices. Further, it is unclear if patients receiving in-center hemodialysis treatment will have a similar experience to patients with diabetes. Finally, little is known about the impact of mentoring on the mentors. Much of extant research has focused on the experiences and outcomes of mentees. Only one study sought to examine the effects on mentors.

## **Theoretical Framework**

### **Social Cognitive Theory**

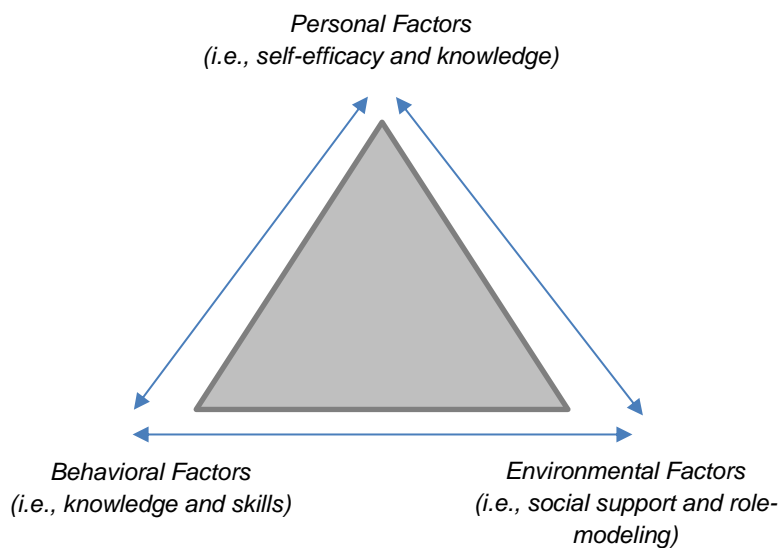
Social cognitive theory provides a framework for understanding how peer mentoring may be a successful intervention for self-management in chronic disease, specifically amongst patients receiving in-center hemodialysis treatments. Social cognitive theory is one of the most widely used models of health behavior and has been used in multiple settings, including the clinical setting for self-management of chronic disease.<sup>69</sup>

Health behavior theories can be used to explain a problem (i.e., an explanatory theory) or to inform how a problem may be addressed (i.e., a change theory), as shown in Figure 2.<sup>70</sup> Social cognitive theory, an interpersonal level health behavior theory developed by Bandura, is both an explanatory and change theory in that it provides a means to understand the problem of chronic disease self-management (e.g., lack of self-efficacy) but also suggests strategies to address the problem (e.g., social support, role models).<sup>69,71-74</sup>



**Figure 2: Types of Health Behavior Theory<sup>70</sup>**

Social cognitive theory suggests that learning occurs dynamically in the social context and is a result of the interaction of environmental factors, behavioral factors, and personal factors. The interaction between these factors is known as triadic reciprocal causation or reciprocal determinism.<sup>69,73-76</sup> The environment, behavior(s), and personal factors interact and influence each other.<sup>73</sup> Personal factors are the individual's ability to determine his actions based on self-determination or self-regulation and analysis of experience. Self-efficacy and

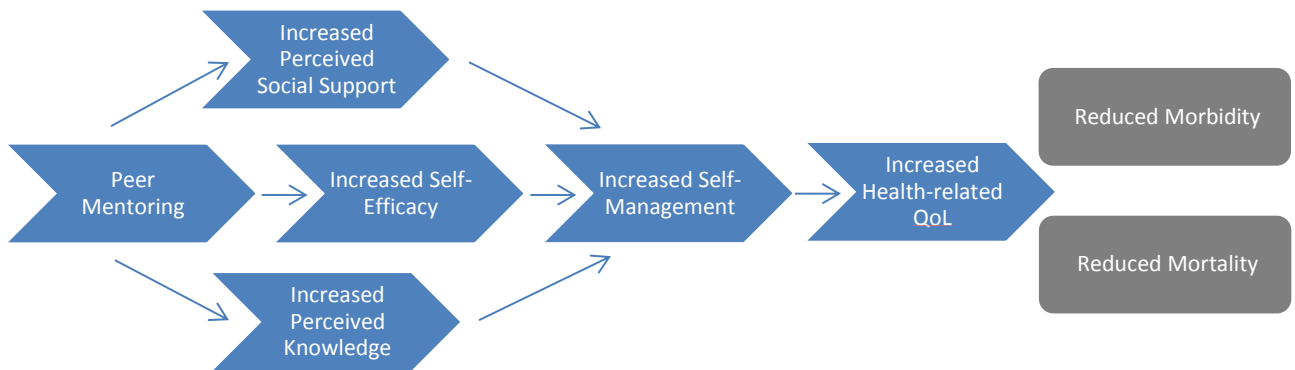


**Figure 3: Social Cognitive Theory: Triadic Reciprocal Causation<sup>73</sup>**

knowledge influence personal factors. Environmental factors can support or discourage health behaviors and may be real or perceived. Environmental influences include observational learning or role-modeling and social support. Behavioral factors are those things that affect health directly, either by promoting health or compromising it. Knowledge and skills, also referred to as behavioral capability, influence behavior. Social cognitive theory posits that these factors are dynamically linked and that changes in any one influence and change the others (Figure 3).

### Psychosocial Constructs to Improve Self-Management

Based on Heisler’s model (Figure 1) as well as social cognitive theory, it is hypothesized that peer mentoring will increase perceived social support and knowledge, thereby increasing self-efficacy and improving self-management behaviors and health-related quality of life.<sup>15,70,71,75</sup> The conceptual model is presented in Figure 4.



**Figure 4: Conceptual Model**

### Social Support

Social cognitive theory suggests that patients need to enlist social support to help them sustain their self-management efforts.<sup>71,75</sup> Social support plays an important role in health outcomes.<sup>77,78</sup> For instance, research suggests that hemodialysis patients’ perception of social support can predict survival.<sup>79,80</sup> Social support has also been linked to increases in self-esteem



and increases in optimism.<sup>81</sup> However, not all social support may be helpful and can even promote barriers.<sup>36,38</sup> What family and friends may identify as support may be perceived as less than helpful by the patient. For example, Palmer's et al. thematic synthesis of patient views from qualitative studies regarding dietary and fluid restrictions indicated that kidney patients can feel policed or scolded by family members about their dietary intake. Patients reported feeling infantilized or patronized.<sup>38</sup> As Heisler indicated in her hypothesized model, emotional support from a peer can provide encouragement, reinforcement, and a decreased sense of isolation.<sup>15</sup> Seemingly, social support from another person who understands what it is like to be a patient may be particularly helpful as that individual understands the unique challenges faced and this can be provided through a peer mentoring program.

## **Knowledge**

As Bandura has stated, "Health habits are not changed by an act of will."<sup>71</sup> Knowledge is a precondition for change and is an important construct in social cognitive theory and chronic disease management.<sup>69,71</sup> Interventions to increase self-management in dialysis have shown some success if they include a cognitive or behavioral/cognitive component.<sup>31</sup> Matteson and Russell identified eight randomized controlled trials in their systematic review, with six showing statistically significant improvement involving a cognitive component.<sup>31</sup> For example, patients find the dialysis diet contradictory to what they have been told is a "healthy diet." Not including a knowledge component, with a clear rationale and practical implementation advice, in a self-management program can leave patients feeling disoriented and confused.<sup>38</sup> Even when knowledge is addressed, with respect to fluid restriction, patients report that they do not understand what they are taught by health care professional until they experience fluid overload for themselves.<sup>36</sup> It is possible that the terminology or feelings of fluid overload described by

someone that has never experienced it may be limited and that another patient or mentor describing how fluid overload actually felt may be more comprehensible. This could potentially eliminate the need for the lived experience and help patients identify symptoms earlier if it does occur. Further, it is possible that the individual delivering the information, whether a health care professional or a peer mentor, may also impact its comprehension (i.e., patients may be more comfortable, at ease, and ready to learn when talking to a peer).

### **Self-Efficacy**

A personal factor, and often considered the core of social cognitive theory, self-efficacy, is one's confidence in their ability to control their behavior. This includes confidence in one's ability to take action, overcome barriers, and perform a task.<sup>71,82</sup> Motivation, mood, and attitudes can be influenced by self-efficacy beliefs; all of which can impact behaviors that influence health.<sup>24</sup> Self-efficacy is generally accepted as the most predictive construct in health behavior.<sup>69,75,83</sup>

Self-efficacy has been shown to be an important construct in chronic disease self-management as it has been associated with improved health status and outcomes in various chronic diseases including arthritis, heart disease, diabetes, asthma, and has been shown to reduce hospitalization through positive changes in health behaviors.<sup>16,22,24,29,78,84-89</sup> Self-efficacy has also been positively correlated with self-management among patients with chronic kidney disease, those on hemodialysis as well as those who have received a kidney transplant.<sup>21,36,90-92</sup> Curtin et al. found that, when controlling for demographic characteristics (e.g., age, education, etc.) and health conditions (e.g., diabetes status, hypertension, etc.), perceived self-efficacy was positively associated with four of five self-management categories (i.e., communication with caregivers, partnership in care, self-care, and medication adherence) measured among patients with chronic kidney disease. It was not associated with self-advocacy. Similarly, research has

suggested that individuals with high levels of self-efficacy typically have better self-management.<sup>90</sup> Interventions with a self-efficacy component were successful when used with patients with kidney failure. A randomized controlled trial that included self-efficacy training regarding fluid intake compliance showed significant increases in self-efficacy and decreases in fluid gain between hemodialysis treatments.<sup>93</sup> A self-management disease intervention piloted amongst hemodialysis patients found significant increase in self-efficacy and self-management whereas additional studies show decreases in hospitalizations, amputations, and improved quality of life among diabetic dialysis patients.<sup>21,28,94,95</sup>

Self-efficacy is influenced through four primary sources: mastery experiences, vicarious experiences, social persuasion, and emotional arousal.<sup>69</sup> Peer mentoring aligns with these influences of self-efficacy. Mentors can coach mentees to try new behaviors, experience small successes and begin to master them. Mentees can learn vicariously from peer mentors and their experiences through observational learning. The vicarious learning experience is enhanced when the mentee sees the mentor as someone similar to himself or as a role-model or leader.<sup>69</sup> Thus, social persuasion provided by someone who is respected and deemed as similar can increase self-efficacy. For example, mentors can persuade mentees to place importance on adhering to their fluid restrictions and reinforce the benefits of limiting fluid, such as no shortness of breath or less cramping during treatment. Finally, a peer mentor can emotionally arouse a mentee by presenting a task in a positive and memorable way as positive emotional states lead to optimistic viewpoints and higher performance.<sup>69</sup> For instance, mentors might suggest a game to help manage fluids or acronym to help mentees remember good sources of protein, both of which can to engage mentees and help them remember a specific self-management tip.

## **Mechanisms of Change**

Social cognitive theory helps to describe the potential mechanisms of change for a peer intervention to increase self-management behaviors among in-center hemodialysis patients. As discussed throughout, the numerous tasks required by this population can be daunting at best, especially for patients newly diagnosed with kidney failure. Simply being told to “do this, restrict that” does not necessarily translate into behavior change. Role-modeling, through observational learning, can help patients better understand how to integrate these new health behaviors into their lives. Thus, it is critically important that the patients (mentees) identify with the role models (mentors) in some way, such as age, gender, race or ethnicity, culture, or socioeconomic group because it can provide them with a belief: “If someone like me can do this, I can do it too.”<sup>69</sup> Peer mentors can demonstrate or share ways they have incorporated the self-management behaviors into their lives and help mentees develop coping skills. This shared experience and forging of new social networks can increase self-efficacy and ultimately improve outcomes.

## **Summary**

Given the success of peer mentoring in other chronic diseases and lack of evidence within hemodialysis, further research is warranted to explore if peer mentoring may be an effective intervention to increase self-management among patients receiving in-center hemodialysis. Dialysis is arguably different from other chronic conditions in that the patients are much sicker, required to make extensive behavior changes (e.g., changing diet, limiting fluids, etc.) to stay alive, and must consistently receive multiple treatments at a facility each week. These could be barriers to a peer mentoring program in that patients may not want to spend additional time focusing on their disease, or these could be the unique features that may make a peer mentoring

program successful in dialysis. Based on the extant literature in other chronic disease, it is hypothesized that a peer mentoring program may have a positive impact on the self-management behaviors of hemodialysis patients. This is further supported by evidence suggesting that patients' stories tend to influence fellow patients' behavior and health care decisions, and in some cases, has more influence than advice provided by physicians.<sup>53,54</sup> Finally, it could be argued that some of this mentoring and support occurs organically within the waiting areas of dialysis facilities or during treatment, as patients typically receive treatment in close proximity to each other. A formalized program expanding this phenomenon and evaluating its impact is needed.

Heisler's model (Figure 1), while not explicitly stated, appears to be based in social cognitive theory as many of the constructs included are fundamental to this theory—self-efficacy, perceived social support, increased positive mood, increased understanding of self-care.<sup>15</sup> However, there is a significant gap in the literature citing the theoretical unpinning to chronic disease management interventions or peer-to-peer interventions. If a health behavior theory is acknowledged, it is usually with a mention of a single construct, such as self-efficacy. This is consistent with the findings of Painter et al. who found that approximately one-third of published health behavior research uses theory and only a small proportion used theory rigorously.<sup>96</sup> While intervention studies were more likely to identify a theoretical framework, nearly 40% did not. As such, this dissertation advances the field as it develops and evaluates a peer-to-peer intervention firmly grounded in social cognitive theory. Further, it seeks to determine the mechanisms of change necessary to improve self-management behaviors within a chronic disease population, that is, determine the key ingredients needed to increase self-management behaviors and thereby provide a theoretical explanation for the relationships posited in Heisler's hypothesized model. It also fills a gap by exploring the use of peers, a cost

effective resource, within ESRD to improve self-management, ultimately improving outcomes and reducing morbidity and mortality.

## **Chapter 3 Methods**

Guided by a review of the relevant literature and corresponding environmental scan, social cognitive theory, formative work conducted at the study site (Appendix B), and feasibility considerations, an evidence-based peer mentoring intervention for in-center hemodialysis patients was developed and implemented from March-June 2015 at a large academic-based facility in Lynchburg, Virginia. Consistent with the feedback from in-center patients, program participants were matched into dyads primarily based on treatment time so that they could meet before or after treatment to discuss topics related to self-management and support. In each dyad, one patient served as the mentor and the other as the mentee.

### **Study Site**

The University of Virginia (UVA) Lynchburg Dialysis facility served as the study site. The UVA Dialysis program is the largest hospital-based program in the country, with nine outpatient units. Specifically, UVA Lynchburg Dialysis is the largest facility within the UVA health system. As the sole provider of in-center hemodialysis services for the community of Lynchburg, there is often a waitlist for new patients.

UVA Lynchburg Dialysis serves approximately 249 in-center hemodialysis patients and 53 home patients six days per week, three shifts per day, and is comprised of five treatment bays containing eight to nine hemodialysis chairs each, for a total of 42 chairs. One isolation chair is available for use by patients diagnosed with Hepatitis B. The facility also supports a home-based peritoneal dialysis program for both continuous cycling peritoneal dialysis (CCPD) and continuous ambulatory peritoneal dialysis (CAPD) as well as nocturnal home hemodialysis

program. Table 2 provides a comparison of the UVA patients to the U.S. patient population. The patient population receiving care at the UVA facility is predominately African American, whereas the majority of patients nationwide are Caucasian. However, it is important to note that African Americans are disproportionately affected by ESRD and have nearly a four-fold increased likelihood of developing kidney failure as compared to Caucasians.<sup>97</sup> UVA also has a higher percentage of patients 70-74 years of age. This may be related to UVA Lynchburg serving as the sole in-center dialysis provider in Lynchburg and, as such, providing care for most of the individuals in the local area, including those in skilled nursing facilities—the nearest facility outside of Lynchburg is located in Amherst, Virginia, which is approximately 16 miles away and not easily accessible due to transportation limitations. Lynchburg also has a larger home program, as compared to the US.

**Table 2: Demographics of UVA Lynchburg Dialysis Patients as Compared to U.S. Patients by Treatment Modality<sup>2</sup>**  
(as of June 1, 2014)

	UVA In-Center	U.S. In-Center	UVA Home	U.S. Home
<b>Age</b>				
49 or less	40 (13.2%)	78,979 (18.4%)	19 (6.3%)	12,406 (2.9%)
50-59	56 (18.5%)	82,999 (19.4%)	12 (4.0%)	8,706 (2.0%)
60-64	27 (8.9%)	52,879 (12.3%)	5 (1.7%)	4,916 (1.1%)
65-69	26 (8.6%)	48,035 (11.2%)	6 (2.0%)	4,344 (1.0%)
70-74	48 (15.9%)	50,303 (11.7%)	8 (2.6%)	3,830 (0.9%)
75-79	22 (7.3%)	28,832 (6.7%)	1 (0.3%)	1,908 (0.4%)
80+	30 (9.9%)	48,065 (11.2%)	2 (0.7%)	2,339 (0.5%)
<b>Sex</b>				
Female	121 (40.1%)	171,964 (40.1%)	21(7%)	17,589 (4.9%)
Male	128 (42.4%)	218,154 (50.9%)	32 (10.6%)	20,890 (4.1%)
<b>Race</b>				
African American	177 (58.6%)	147,701 (34.5%)	30 (9.9%)	10,189 (2.4%)
Caucasian	67 (22.2%)	214,277 (50%)	21 (7.0%)	25,249 (5.9%)
Native American	1 (0.3%)	5,841 (1.4%)	0 (0%)	439 (0.1%)
Asian	1 (0.3%)	20,108 (4.7%)	1 (0.3%)	2,463 (0.6%)
Other	3 (1.0%)	1,721 (0.4%)	1 (0.3%)	106 (0.0%)
<b>Total</b>	249 (82.5%)	390,121 (91.0%)	53 (17.5%)	38,479 (9.0%)



## **Intervention and Evaluation Overview**

A P2P intervention for in-center hemodialysis patients launched at the UVA Lynchburg facility on March 4, 2015 and ended on June 28, 2015. The P2P intervention included mentee and mentor pairing, mentor trainings, kick-off mixers, ongoing meetings, mentor training boosters, and a final celebration mixer. It was preceded by a social marketing effort, which included a naming contest, and participant recruitment.

Participants were asked to meet approximately four times per month, or once per week. Meetings could be in-person or by phone, email, or text; however, patients were encouraged to hold at least two face-to-face meetings each month. The content discussed and length of the meetings was driven by the participants and their specific self-management needs at the time of the interaction. All mentors were required to complete a 5-hour training prior to being matched with a mentee. During this time, mentors were provided with an outline or “sample peer time” flow for a meeting (i.e., greeting and welcome, ask about self-care in past week, point out and congratulate good self-care, check in about expectations, and ask for and work together on one concern or challenge), with topic suggestions and probes during the mentor training. Mentors were asked to submit a log detailing each interaction—date, location of meeting, length of interaction, topics discussed, educational materials used, and referrals to staff.

A single arm evaluation study using a quasi-experimental research design with repeated measurements over three time periods and patient participants serving as their own controls was used to evaluate the program. The combined process and outcome evaluation provided preliminary evidence on the feasibility of implementing P2P programs in dialysis facilities and examined the impact of P2P program on measures of patients’ psychosocial health. As described in more detail in subsequent sections, process data, including the number of mentors and mentees

completing the program, satisfaction with the program, and resources needed for program implementation, was collected along with knowledge and psychosocial outcome data (e.g., perceived social support, dialysis social support, self-efficacy, dialysis self-management behaviors, and health-related quality of life) to evaluate the program's implementation and impact. Data collection extended from March 2015 through June 2015 at the following time points: mentors' pre-training assessment (T0), mentors' post-training/pre-intervention and mentees' pre-intervention assessments (T1), and mentees' mid-program assessment (T2) and mentors' and mentees' post-intervention assessments (T3). Figure 5, Program Logic Model, highlights the inputs (e.g., staff time, participants, and materials such as giveaways and educational handouts), outputs (e.g., promotional and recruitment materials, trained staff to deliver program, and mentor/mentee meetings), short-term outcomes (e.g., knowledge, self-efficacy, perceived social support, dialysis social support, and dialysis self-management behaviors) and long-term outcomes (i.e., reduced morbidity and mortality) that were anticipated prior to program implementation. Time did not allow for the assessment of the long-term outcomes during this study.

## **Peer Mentoring Intervention**

### **Participant Eligibility**

Patients were eligible to participate in the intervention if they had been diagnosed by a physician with ESRD and were receiving in-center hemodialysis treatment at the UVA Lynchburg Dialysis facility. All participants must have been adults ( $\geq 18$  years of age), able to provide informed consent, and willing to commit for the duration of the study, through June 30, 2015. This included willingness to participate in all ongoing assessments and program evaluation activities (e.g., completing logs and surveys, etc.). Participants must have also been able to

comprehend English without the aid of a support person. Patients with a physician diagnosis, as documented in the electronic medical record (EMR), of mental illness, including major depression, dementia, Alzheimer's disease, schizophrenia, bipolar disorder, alcoholism, or drug abuse, were ineligible to participate. Individuals with an intellectual disability, as diagnosed by a physician and noted in the EMR, were also deemed ineligible.

Additionally, mentors must have received treatment at UVA Lynchburg Dialysis for one or more years, with at least six months of their treatment performed in-center. This time-related treatment requirement increased the likelihood that mentors were familiar with the facility, its staff, and its policies. In addition to completing all training activities associated with the program, they must have been willing to dedicate the time necessary to provide ongoing one-on-one support to another patient in the UVA Lynchburg Dialysis facility. All patients interested in participating were asked to submit an application eliciting this information, which helped the Principal Investigator (PI) determine eligibility. Time requirements related to eligibility were confirmed by facility staff using the patient's EMR. The program application is provided in Appendix C.

### **Participant Recruitment**

The study was promoted to in-center hemodialysis patients through various channels within the facility, including flyers, electronic messages on the waiting room television monitor, and brochures. To build excitement and interest about the P2P program, the PI conducted a project naming contest. This not only engaged staff and patients, but also helped to establish a sense of ownership of the program. Promotional posters and flyers explaining the P2P program and introducing the contest were dispersed throughout the clinic in mid-October 2014 inviting all patients and staff to submit names via a suggestion box. Three ballot boxes were strategically

placed in high traffic areas with forms next to them that included an explanation of the program, outlined the contest, and solicited suggestions for names. A total of 73 names were submitted from staff and patients and those comprised the voting ballot. Patients and staff were then asked to vote for their favorite name. A total of 166 votes were received during the 4-day voting period. Because there was a tie, two winners were selected. The first winner, a facility social worker, submitted the name “Peer Up!” The second winner, an in-center hemodialysis patient, submitted “Together Makes Us Better.” The PI combined the two submissions to create the official program name: *Peer Up! Together Makes Us Better*. The winners and their submissions were announced during the monthly staff meetings in November 2014. Additionally, the patient was awarded a Walmart gift card for her submission (facility staff was not eligible to win the gift card). *Peer Up! Together Makes Us Better*, and a subsequently designed logo, was used on all program materials and helped to brand the program.

Bolus participant recruitment occurred during January and February 2015 and included a promotional flyer (Appendix D) and brochure (Appendix E), announcements via a lobby bulletin board, an informational table in the lobby, and identifying and approaching new patients. Promotional flyers and brochures were posted throughout the facility, specifically in areas with high patient traffic, including the waiting area and the dialysis vascular access washing station. (Most patients stop at this area to wash their vascular access prior to going to their treatment chair.) A bulletin board in the lobby was used to promote the program, including announcing the program and posting important dates for participation. An information table in the lobby waiting area was also set up and staffed by the PI during peak times (e.g., shift change). Patients were personally approached in the lobby by the PI while waiting for their treatment to begin. All patients interested in participating in the intervention were asked to complete an application

which determined participation eligibility and captured information that would help match the participant into mentor/mentee pairs (see Mentee/Mentor Pairing for detailed information about the pairing process). If a participant was unable to complete the application on his or her own, the PI would assist. New patients, defined as those at the facility for three months or less as determined by staff via the electronic medical record, were also approached to participate as mentees as they tend to have higher rates of hospitalization and mortality.<sup>98</sup>

Facility staff were also asked to recommend mentors, or those patients deemed to be empathic, accepting of others, and in good health as well as mentees, or those patients identified as struggling with dialysis self-management. Staff could nominate someone either by speaking to PI or by completing a nomination form (Appendix F). Staff were briefed on eligibility requirements during the December 2014 staff meeting and copies of the nomination form distributed. A nomination collection box was set up in the staff break area. Any patient identified as new or nominated by a staff member was approached during his/her treatment time by the PI. The PI introduced herself; asked if the patient had heard of the peer program, and if s/he would be willing to talk for a few minutes about the program. Patients were told that they were nominated by facility staff and the program described to them. A recruitment brochure and application was left with each nominated patient for them to review. The PI then followed up with each patient during his/her next treatment time to see if s/he had any questions, had decided to participate, and, if so, needed assistance completing the application.

Recruitment for mentors and mentees was completed primarily in tandem; however, the majority of mentors were recruited first. This was because all mentors had to complete training in order to participate. Each mentor was to be paired with one mentee and it was important to try to match the numbers of trained and eligible mentors with eligible mentees. Mentors were asked

to dedicate a significant amount of time for training and it was anticipated that some may drop out, not complete the training, or be deemed as unqualified (see Mentor training for more information about training sessions). The PI felt it was important that all mentees recruited and eligible be paired with a mentor with which to meet.

### **Mentor Training**

All mentors were required to successfully complete a 5-hour training session. Mentors were able to select the training time and format that fit best with their schedule, either two 2.5-hour sessions or one 5-hour session. Sample agendas are included in Appendix G.

The mentor training session(s) focused on topics including leadership, communication skills and relationship building, the difference between medical information and medical advice, privacy and confidentiality, and basic kidney disease information. These topics were consistently mentioned as topics of concern and/or barriers to peer mentoring during the key informant interviews conducted via the environmental scan summarized in chapter 3 and described more thoroughly in Appendix A. Primarily a skills-based and experiential training, mentors learned content through demonstration and role-plays. By the end of the training, mentors were able to: describe the role and commitment of a peer mentor; establish rapport during a meeting with a mentee; demonstrate active listening techniques; demonstrate the use of communication skills through role play; describe appropriate professional boundaries in mentor-mentee relationships; list at least five situations when referral to the care team is be recommended; and define privacy and confidentiality as it related to peer-to-peer interactions.

Mentors received a certificate of completion and distinction as a “*Peer Up!* Mentor” if they successfully completed the mentor training. To successfully complete the training, they had to demonstrate at least 80% of communication skills learned in a role-play with a fellow

participant. This was evaluated by the PI using the role-play evaluation form in Appendix H. Successful mentors also had to report “somewhat confident” or better on at least 10 of the 12 mentor tasks on the training evaluation form in Appendix I.

Any mentor not meeting all of these benchmarks or deemed unfit based on comments made during the training would have been excused from the program. For example, a mentor-in-training appearing disgruntled and complaining about the facility staff throughout the training would have been asked to meet with the PI to discuss continued participation as this type of behavior would be considered counter-productive when meeting with a mentee. No situations like this were encountered and all mentors successfully completed the mentor training.

Facility staff also assisted with the development of the training content. UVA Lynchburg social workers, dietitians, and charge nurses reviewed the mentor training curriculum and provided feedback. When possible, existing UVA Lynchburg education materials were used in order to keep messages consistent for the patients. Any new patient materials were thoroughly reviewed and approved by the appropriate individuals. For example, dietitians reviewed dietary handouts. They also assisted with food purchased for consumption during the training sessions.

### **Mentee/Mentor Pairing**

Participants were paired with a mentor on the same treatment shift so that they were able to meet before or after treatment at the dialysis facility simply because transportation to/from treatment was a substantial barrier to participation. Many patients at UVA Lynchburg Dialysis are unable to drive or uncomfortable driving themselves and rely on medical transport or friends/relatives. However, if transportation was not an issue or multiple participants were available for pairing during a particular shift, additional considerations and characteristics were taken into account, including age, gender, hobbies, level of communication apprehension, etc.

obtained from the program application. For example, participants with similar levels of communication apprehension were paired together. This was an attempt to prevent one individual from monopolizing the peer meetings. Further, the PI had planned to meet with any individuals seeking to serve as mentors but indicating a high level of communication apprehension to determine overall participation and possibly encouraged to the individual to participate as a mentee; however, no such situation was encountered. Communication apprehension was assessed using the dyadic sub-set of questions adapted from the Personal Report of Communication Apprehension (PRCA-24).<sup>99</sup> Facility social workers and other staff reviewed the suggested pairings with the PI as they knew the patient population better and provided input. Pairs were finalized and the participants were invited to the social mixers.

### **Program Launch/Social Mixers**

The initial social mixers served as the official program launch and provided participants with their first opportunity to meet their respective mentor/mentee. Mixers were scheduled at times when *both* the mentor and the assigned mentee had transportation and could attend. Multiple mixers were held at various times so that all participants could attend. During the mixers, a program overview was provided, including a review of the program length, the suggested number of interactions between mentor and mentee, and suggested places to meet (e.g., at facility or off-site). Confidentiality as well as medical advice versus medical information was also reviewed. All participants were asked to sign a confidentiality agreement (Appendix J). Participants also received their *Peer Up!* program giveaways, including branded hand sanitizer, hard candy (sugar-free for patients with diabetes), crazy socks, branded grocery bag, branded t-shirt, and notebook. Finally, participants whose mentee/mentor also attended were introduced and held their first meeting. All mixers occurred during the first week of March 2015.



## **Mentor/Mentee Interaction**

During the four months of program implementation, dyads were encouraged to interact at least once per week either in-person or by phone/email. At least two interactions per month were in-person, for a total of at least eight in-person interactions. Additionally, dyads were encouraged to interact as much as each individual pair deemed appropriate and not unduly burdensome. All interactions were to be logged by the mentor to capture frequency, duration, and format (e.g., in-person, phone, email, etc.). The mentor/mentee interaction log can be found in Appendix K

Pairs meeting the suggested number of times in a month, as evidenced by their contact logs, were entered into a monthly drawing for a \$25 gift card for each individual. Those pairs qualifying for a monthly drawing were also entered into a grand prize drawing, held at the final celebration mixer, for a \$100 gift card per individual. This incentive was provided to encourage participants to meet as well as to complete and turn in their logs.

A quiet, private space for peers to meet was set up in the facility waiting area. While interaction on a non-treatment day was cited as the preferred time during the formative phase, it was not be feasible for all patients because of transportation limitations. Nevertheless, dyads that preferred to meet on a non-treatment day and had access to transportation were able to do so. The location of each interaction was logged by the mentor on the contact log.

Mentors were given a sample peer time agenda, including a list of dialysis self-management behaviors (e.g., fluid restrictions, diet, etc.), in the form of a pocket card during the mentor training. Mentors were advised to use this sample agenda to start an interaction with a mentee. Mentors were encouraged to discuss the topic that was most pertinent for the mentee at that given time. The pocket card was to serve as a starting point for a discussion until the mentor/mentee relationship developed and interactions became more natural.

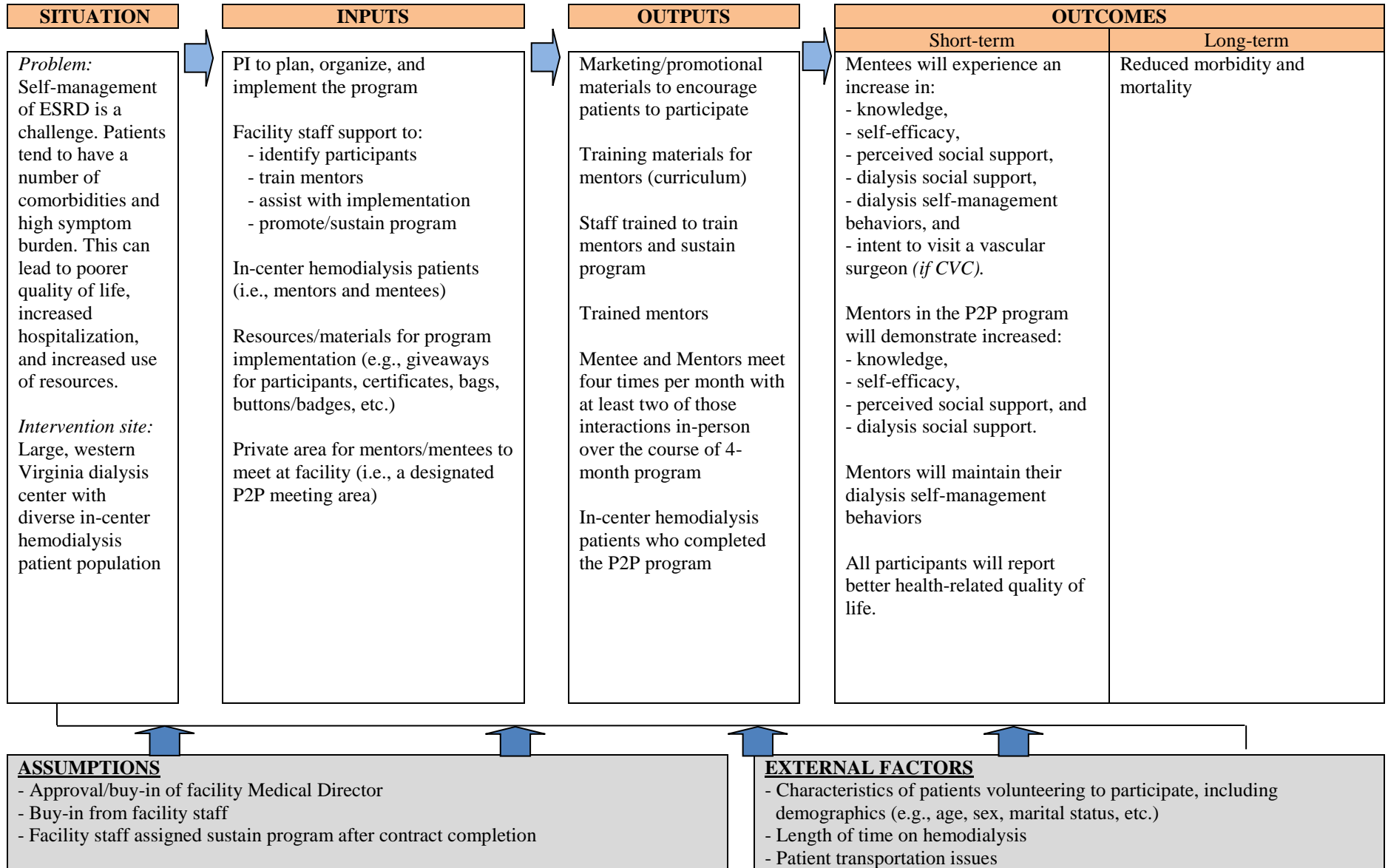
### **Mentor Training Boosters**

Mentor training boosters were conducted on May 6 and May 9, 2015. Mentors were asked to attend one of the 2-hour sessions. The booster sessions served as a check-in and problem-solving opportunity for mentors struggling to connect with their mentees. Kidney disease and dialysis information was also reviewed.

### **Final Celebration Mixer**

The final celebration mixer was held on Sunday, June 28, 2015 at a local restaurant. Transportation was provided for those who required it to attend. Those completing the intervention received certificates of recognition and the grand prize drawing was held for the \$100 gifts referenced earlier. For pairs present, this served as the last official meeting; however, mentors and mentees were free to continue meeting, if mutually agreeable.

**Figure 5: Logic Model of Peer-to-Peer Program**



## **Evaluation of the Intervention**

The single arm evaluation study used a quasi-experimental design with repeated measurements over three time periods and patient participants serving as their own controls. The combined process and outcome evaluation provided preliminary evidence on the feasibility of implementing P2P programs in dialysis facilities and examined the impact of P2P program on measures of patients' psychosocial health. As described in more detail below, process data, including the number of mentors and mentees completing the program, satisfaction with the program, and resources needed for program implementation (Aim 1), was collected alongside psychosocial outcome data (Aims 2 and 3) to evaluate the program's implementation and impact. Data collection extended from March 2015 through June 2015 for the following time points: mentors' pre-training assessment (T0), mentors' post-training/pre-intervention and mentees' pre-intervention assessments (T1), and mentees' mid-program assessment (T2) and mentors' and mentees' post-intervention assessments (T3). Table 3 depicts the study timeline with corresponding activities. Participants were required to complete a consent form (Appendix L) prior to joining the study and participating in any of the activities. This study was submitted to the Institutional Review Boards for both the University of Virginia and Virginia Commonwealth University and was deemed to not be human subjects research. The official documentation from each institution can be found in Appendices M and N, respectively.

### **Power Calculation**

A power analysis, using G\*Power 3.1.9.2 determined that 40 subjects (i.e., 20 mentors and 20 mentees) were needed to detect an effect size of 0.30, at 80% power and an alpha level of 0.05. An effect size of 0.30 (considered a medium effect size) was selected because it is regarded as a clinically significant change in self-efficacy for patients with chronic disease.<sup>29,67</sup> As such,

the PI sought to recruit approximately 48 – 50 patients, with at least 24 recruited as mentees and at least 26 recruited as mentors, to account for attrition. This represented approximately 20% of the in-center hemodialysis patient population at UVA Lynchburg Dialysis.

### **Aim 1**

To evaluate the implementation of a P2P program for patients treated in one western Virginia dialysis center.

**Data Collection.** The goal of this process evaluation was to track program participants' (i.e., mentors and mentees) completion of study procedures, attendance at events, and overall satisfaction with their experience in the program, as well as the staff and facility resources needed to support the program's implementation. An intervention log was created and maintained to track the number of applications received, the number of mentors and mentees enrolling in the study, and the number deemed ineligible to participate with the corresponding reason why. The number of participants by role (i.e., mentor or mentee) that complete the 4-month program was also tracked. Completion is defined as participation across the 4-month program implementation period and completion of all assessments. Additionally, the number of patients completing the mentor training was documented in intervention log. Each mentor was asked to complete an evaluation at the end of the mentor training session.

Mentor and mentee interactions were also tracked. Mentors were asked to complete a visit log after each interaction with a mentee. Data, including whether the interaction was face-to-face, phone, or email, the date the interaction took place, the length of the interaction, where the interaction took place, the topics discussed, and any additional comments about the interaction was documented by the mentor immediately following each visit. The total number of

interactions per pair as well the total number for the overall project was documented in the intervention log.

Surveys were collected from mentors, mentees, and facility staff. Specifically, patient participants were asked questions assessing overall satisfaction with the P2P program and to note specific aspects of the program most and least liked during the final celebration mixer in June 2015. The survey of facility staff gauged overall impressions of the program, including time and resources (including resources used and those desired but perhaps unavailable), and perceptions of patient impact and satisfaction. The survey was administered during the monthly staff meeting held in July 2015.

**Data Analysis.** Data from surveys and evaluations were tabulated to determine satisfaction with training as well as with the overall P2P program. Program evaluation instruments for mentees and mentees are included within Appendices O and P, respectively. Further, the intervention log, created and maintained within Microsoft Excel, was used to provide context for interpreting the results related to the subsequent aims. Quantitative data were uploaded into SAS 9.3 and validated for data integrity (e.g. checked for duplicates, outliers, and invalid values).<sup>100</sup> Descriptive statistics were reported, including means and standard deviations for ordinal- and interval-level data and counts and corresponding percentages for categorical- and nominal-level data. Thematic qualitative analysis was used to identify core themes from qualitative data. The PI and a colleague at the Mid-Atlantic Renal Coalition independently reviewed and hand coded all open-ended responses. They met to discuss coded responses and reach consensus on any discrepancies. Related codes were assigned into larger categories and overall themes were generated.

Data were reviewed throughout the intervention period, giving the PI a sense of how implementation was faring and afford the opportunity of making any necessary adjustments during program implementation. Because this was a pilot study, no benchmarks existed and thus this process evaluation was exploratory.

Table 3: Study Timeline		2014		2015												
		N	D	J	F	M	A	M	J	J	A	S	O	N	D	
Proposed Activities & Time Periods		Program Development				Implementation				Data Analysis			Write Results			
<b>Program Development &amp; Study Recruitment</b>																
Develop study procedures, tracking databases and logs, assessments/surveys, training curriculum, program procedures, and educational materials		X	X													
Identify and train facility staff to serve as training facilitators				X	X											
Mentor recruitment and training				X	X											
Mentee recruitment					X											
<b>Process &amp; Outcome Evaluation</b>																
Process (Aim 1)	Implementation log ( <i>participation rates, training attendance, program completion</i> )			X	X	X	X	X	X						X	X
Process (Aim 1)	Mentor training surveys				X										X	X
Process (Aim 1)	Mentor/mentee surveys ( <i>program perceptions and satisfaction</i> )								X						X	X
Process (Aim 1)	Center staff surveys ( <i>program perceptions and resources used</i> )								X						X	X
Outcome (Aims 2 & 3)	Pre-Intervention data collection T0: Mentors pre-training T1: Mentors post-training Mentees pre-intervention				X	X	X								X	X
Outcome (Aims 2 & 3)	Mid-intervention data collection T2: Mentees mid-intervention							X							X	X
Outcome (Aims 2 & 3)	Post-intervention data collection T3: Mentors and mentees post-intervention								X	X					X	X
<b>Data Analysis</b>																
Analyses All Aims	Data organization, cleaning, and analysis				X	X	X	X	X	X	X	X				

## Aim 2

To evaluate the impact of the 4-month P2P program psychosocial health indicators.

**Data Collection.** Psychosocial health indicators, including self-efficacy and perceived social support, as well as dialysis knowledge, was assessed via paper/pencil survey. A survey was selected as the data collection method, but patients were able to request assistance from the

PI if they required it during completion. Because limited health literacy has been documented within the dialysis population, validated scales with a readability level at or below 6<sup>th</sup> grade were used.<sup>101,102</sup> The Flesch-Kincaid Grade Level Formula was used to assess the readability of all instruments and materials used with patients to ensure they were at or below 6<sup>th</sup> grade reading level. Participants were asked to complete the assessments when they arrived at the facility, before beginning their treatment or shortly thereafter, because of concerns dialysis-associated cognitive impairment.<sup>103,104</sup> Participants were given an informed consent form and asked to sign it prior to enrolling and engaging in any study procedures (e.g., surveys, trainings, etc.).

The survey (Appendix Q), administered at three distinct time points, was comprised of four validated scales, with additional questions relating to demographics, and vascular access (Table 4). Psychosocial variables were ascertained from self-reported data obtained from mentees via survey pre-intervention (T1), mid-intervention (T2), and post-intervention (T3).

**Table 4: Survey Timeline by Role**

<b>Time Points</b>	<b>Participant Role</b>	<b>Administration Dates</b>
T0: Pre-Training	Mentors	02/25/15 – 03/08/15
T1: Post-Training	Mentors	02/25/15 – 03/08/15
T1: Pre-Intervention	Mentees	03/04/15 – 03/07/15
T2: Mid-Intervention	Mentees	05/07/15 – 05/09/15
T3: Post-Intervention	Mentors & Mentees	06/28/15 – 06/30/15

Descriptions of the variables used to assess the program’s impact on mentees’ psychosocial outcomes are described below. The variable and its corresponding questions on the survey are provided in table 5. It was hypothesized that program participation would lead to changes in these short-term outcomes, which would ultimately drive long-term outcomes; however, long-term outcomes were not assessed during this study. See the program logic model in Figure 5 for the hypothesized short-term and long-term outcomes.



**Table 5: Outcome Variables**

<b>Variable</b>	<b>Survey</b>
<i>Short-term Outcomes</i>	
Self-efficacy	Q5a-f
Perceived Social Support	Q7a-h
Dialysis Social Support	Q8a-d
Knowledge	Q6a-w
Dialysis self-management Behaviors	Q4a-f
Vascular access	Q3-3a
Health-related Quality of Life	Q9
<i>External Factors</i>	
Years receiving ESRD treatment	Q1-2
Demographic Characteristics	Q10-17

A. Dependent variables (short-term outcomes)

- a. Self-efficacy: Self-efficacy or confidence managing disease was ascertained through self-report data using the Self-Efficacy for Managing Chronic Disease 6-item Scale. Respondents were asked to rate their confidence on a 10-point Likert-type scale (*1-not at all confident/10- totally confident*) across multiple domains, including symptom control, role functioning, and communicating with physicians. This scale, developed by Lorig et al., has demonstrated acceptable internal consistency reliability as assessed via Cronbach’s alpha ( $\alpha = .91$ )<sup>85</sup> and has been used with dialysis patients in other research studies.<sup>90,94</sup> The score was the mean of all six items, with higher scores indicative of higher self-efficacy. Scores for individuals missing two or more responses were not calculated.
- b. Perceived social support: The Social Support Subscale (Emotional/Informational) from the Medical Outcomes Study (MOS-SSS: Emotional/Informational) was used to measure participants’ level of perceived social support. The 8-item scale asked participants to estimate how often someone is available to offer social

support in different situations, on a 5-point Likert scale (*1-none of the time/5-all of the time*). This scale was originally developed by Sherbourne and Stewart (RAND Corporation) and has demonstrated exceptional internal consistency reliability ( $\alpha = .96$ ).<sup>105</sup> The total score was the mean of all eight items, with higher scores indicative of higher perceived social support. Scores for individuals missing two or more responses were not calculated.

- c. Dialysis social support: A unique aspect of this program is peer support offered by other dialysis patients; however, no validated scale currently exists to capture perceived social support within the dialysis setting. To this end, a 4-item, 5-point Likert-type scale (*1-none of the time/5-all of the time*) was created assessing social support in the dialysis setting. Items were summed and divided by total number of responses to generate a mean, with higher scores indicative of higher perceived social support within dialysis. Scores for individuals missing two or more responses were not calculated.
- d. Knowledge: Participants' knowledge of dialysis self-management was measured using the 23-item multiple choice, Chronic Hemodialysis Knowledge Survey (CHeKS), developed by Cavanaugh, et al. The internal consistency, using Kuder-Richardson coefficient of reliability (KR20), is 0.79.<sup>106</sup> The knowledge composite score was generated by summing the correct responses, with higher scores indicative of higher knowledge.
- e. Dialysis self-management behaviors: To measure how often participants have completed the common self-management behaviors associated with dialysis, a 6-item scale was developed which asked them to rate how frequently they have

carried out a specific behavior (i.e., coming to dialysis treatment the prescribed number of times per week, completing the full treatment time each treatment, adhering to prescribed diet, following fluid restrictions, taking all medicines, and taking medicines on a set schedule) on a 5-point Likert-scale (1-none of the time/5-all of the time). Items were summed and divided by total applicable items generate a mean, with a higher mean indicating higher frequency of self-care behaviors. Scores for individuals missing two or more responses were not calculated. A higher score indicated higher frequency of self-care behaviors.

- f. Vascular access: As described previously, the preferred vascular access for hemodialysis is an AVF.<sup>42</sup> Because AVFs require time to mature and become usable, it is highly likely that if a patient has an AVF placed during the study, s/he would not be able to use it until after the study is complete. Therefore, respondents were asked to indicate the type of vascular access they use for dialysis. Specifically, participants using a CVC, the type of vascular access typically associated with highest infection rates and poorest outcomes,<sup>43</sup> were asked about their intentions to have a consultation with a vascular surgeon to have an AVF placed (Likert-item developed using the Transtheoretical Model of Behavior Change<sup>75</sup>).
- g. Health related quality of life: The Health Related Quality of Life question from the Medical Outcomes Study (MOS) was used to measure participants' perceived health status. This single Likert scale item asked participants' to rate their health from "excellent" to "poor" (i.e., excellent=1, very good=2, good=3, fair=4, and

poor=5). This item was originally developed by Ware and Sherbourne (RAND Corporation) and has been deemed a valid, single-item measure.<sup>107-109</sup>

## B. External factors

- a. Years receiving ESRD treatment: Total amount of time receiving treatment was calculated using CMS Form #2728: ESRD Medical Evidence Report Medicare Entitlement and/or Patient Registration. Participants were also asked the month and year they began receiving treatment for ESRD on the assessment. Responses were used to supplement what was available from the facility regarding length of time on dialysis.
- b. Patient characteristics: Additional demographic information regarding age, sex, marital status, race, ethnicity, employment, education, and income was also collected from mentors and mentees

**Data Analysis.** The PI coded the data using the coding manual and entered it into an Excel spreadsheet. Once entered, a colleague reviewed the coding and checked the hard copy against the electronic entry. Data entry errors were minimal (<1%) and corrected.

Missing survey data were examined for patterns. Minimal survey data were missing (<1%) and exhibited no patterns. Person-mean imputation was used to estimate missing values for survey responses, after consultation with a biostatistician.

Descriptive statistics were prepared to answer the research questions related to program implementation and process evaluation. Descriptive analyses were conducted to characterize baseline information on self-efficacy, perceived social support, knowledge, and participant demographics. Categorical data (e.g., race, sex) are reported as percentages whereas continuous data (e.g., self-efficacy, knowledge scores) are reported as means, medians, standard deviations,

and ranges. Ordinal data (Likert-scaled scores) was examined to determine the appropriate analytic approaches to be used (e.g., if data were skewed, a dichotomous variable would have been created using the median or mean, as appropriate).

To test the Aim 2 hypotheses, a single-arm pilot intervention study design with repeated measurements over three time periods was used, paired with repeated measures ANOVA (analysis of variance) in the case of parametric data and Friedman's test in the case of non-parametric data. Repeated measure designs are generally considered to be appropriate when: (1) monitoring change in participants over time; (2) there are a limited number of study subjects with potential for large variation between subjects resulting in a large error variance when using a standard ANOVA; and (3) efficiency is a consideration. Efficiency derives from the fact that with repeated measures ANOVA, each study subject serves as his/her own control and is measured under all conditions (i.e., times). This design made it possible to isolate the variability between subjects and focus on treatment effects (the within subjects factor). This allowed for more power to detect change in the primary short-term outcome variable (self-efficacy) with fewer subjects.

All data were reviewed for compliance with the assumptions for repeated measures ANOVA. If any assumption(s) was violated, a nonparametric test, the Friedman Test, was used. If assumptions were satisfied, a series of repeated measures ANOVAs was performed using SAS<sup>®</sup> Proc Mixed with different covariance structures to find the best fitting model for the data. The model with the lowest Akaike's Information Criterion (AIC) in the fit statistics, indicating a better fit, was selected for the analysis.

### **Aim 3**

To evaluate the impact of the 4-month P2P program on mentors' psychosocial health indicators.

**Data Collection.** Self-reported data obtained via survey were also used to assess the psychosocial health of the mentors. Measures of knowledge and psychosocial health were defined the same as those for mentees. Surveys were administered to mentors at three distinct time points—pre-training (T0), post-training (T1), and post-intervention (T3).

The hypotheses that mentors will demonstrate increased perceived social support, knowledge, and self-efficacy, and maintain their self-reported frequency of dialysis self-management behaviors as compared to baseline measures was tested using repeated measures ANOVA over the three time periods. The same data protocol described under Aim 2 was applied to the mentor data as well.

**Data Analysis.** The same procedures described in Aim 2 were followed in Aim 3.

### **Data Management**

All survey data were entered into Excel for uploading as a CSV file into SAS. A data dictionary describing each of the variables was developed as well as protocols for handling outliers, data entry errors, and data corrections. Since less than a 5% data entry error was found, data did not need to be re-entered. All completed surveys were stored in a locked file cabinet as this process was completed. All paper instruments were destroyed after data entry processes were completed.

## **Chapter 4 Results**

This chapter provides the results of the program evaluation. The goal of this evaluation was to determine the impact of a 4-month P2P program introduced in one western Virginia dialysis center on patients' psychosocial health outcomes. Results are presented by specific aim.

### **Aim 1**

To evaluate the implementation of a P2P program for patients treated in one western Virginia dialysis center.

#### **Recruitment, Participation, and Attrition**

In total, 30 mentor applications and 27 mentee applications were received. The program launched with 23 mentors and 23 mentees. A total of 21 mentors and 22 mentees completed the program. The mean age of mentees was 56 (SD=12.85) years and mentors was 57 (SD=15.49) years. Age breakdown by role is provided in Table 6. Years receiving treatment for ESRD is also provided in Table 7. Fifty two percent of mentees had been receiving dialysis for a year or less as of March 1, 2015. As demonstrated in Table 8, more females served as mentors whereas the distribution was more equitable among mentees. The majority of the *Peer Up!* participants were African American, which is consistent with the overall demographics of the center. Very few individuals were married or were cohabiting; primarily patients lived alone. The majority of mentees and mentors had a high school diploma or less, although some mentors did have some college with one reporting a Master's degree. Few individuals were employed and those who were employed worked part-time.

Four social mixers were scheduled, but only three were held due to weather. Mentors were to attend the same social mixer as their assigned mentees as the social mixer was to serve as their first interaction. Varying participants' schedules required four mixers be held. Originally scheduled for March 3 and 4, the dates were pushed back one day to March 4 and 5 so that the PI had more time to finalize the pairings once all mentors completed training. This also allowed more time for the pairings to be reviewed with the facility staff and any recommended adjustments could be made. Eighteen individuals attended a social mixer. Weather was a significant barrier and resulted in the cancellation of the last scheduled social mixer. Treatment schedules and transportation were also barriers; however, the facility staff was very accommodating and adjusted patients' treatment time so that they could attend a mixer. Participants who were unable to attend a social mixer were visited chairside during their treatment time to complete necessary paperwork and review the program.

During the final mentor training session, one individual stated that she realized how much she did not know about the facility and dialysis, and that she should have been a mentee. Similarly, after an initial meeting at a social mixer, a mentor suggested that the mentee she was paired with should have been a mentor as he had been on dialysis for some time and knew a great deal. The PI was able to respond to these statements, train the mentee to be a mentor, and adjust the participant pairings accordingly.

One mentor resigned from the *Peer Up!* program on May 1, 2015, because she found her mentee to be unresponsive to phone calls. The pair had met twice, but did not seem to connect. The mentee was new, just beginning in-center hemodialysis on February 4, 2015, and overwhelmed. The mentor took the lack of response personally and decided to quit the program.



The PI inquired if the mentor would want to mentor someone else since she had invested her time and had completed training, but she declined.

The mentee expressed that she wanted to remain in the program even though she did not establish a working relationship with her assigned mentor. Therefore, she was re-assigned to the patient consultant working on the project. The consultant was a patient at the center prior to receiving a kidney/pancreas transplant approximately two years ago. She joined the project in February 2015, after UVA Lynchburg staff recommended her. She was a trained social worker specializing in conflict resolution and family issues. The consultant had previously met with the mentee a number of times to encourage her to meet with her mentor and return calls. This resulted in a relationship forming between the consultant and the mentee.

Two other participants, a mentor and a mentee, were unable to complete the program due to significant illness and/or hospitalizations occurring in late May and June. Some phone contact was reported between these dyads during the illnesses and subsequent hospitalizations; however, neither was able to complete the final survey due to altered mental status or severe depression.

### **Mentor Training**

Of the 30 individuals submitting an application to serve as a mentor, six did not complete a training session. Two individuals were scheduled and re-scheduled for various training sessions, but never attended. The PI followed up with each of these individuals and determined that personal commitments, including work and family, prevented them from completing the training. The remaining individuals indicated that they changed their minds and no longer wanted to participate, or were unable to participate due to personal and/or health issues.

The program launched with 23 active mentors. Results of the mentor training evaluations are provided in Tables 9 and 10. Participants rated the overall training experience highly,

“strongly agreeing” or “agreeing” with a majority of the statements on the evaluation form. Two participants disagreed that there was enough time to practice new skills and openly stated that they would have liked more opportunity to role-play during the training. One participant strongly disagreed that the handouts were clear and easy to read. Participants self-reported confidence in performing the skills associated with being a mentor, such as using open-ended questions and keeping information private was also rated highly by participants, either as “totally confident” or “somewhat confident.” One participant did not feel very confident about naming three characteristics of a good mentor and one participant did not feel very confident about defining “stages of change.” No items were rated as “not at all confident”. A common theme expressed verbally by some participants was that they were hesitant to commit to the program because of the length of time required for the training, but they were very happy they decided to do it. They mentioned that they learned a great deal and enjoyed the opportunity to meet some other patients that they had not met before.

### **Mentor/Mentee Interactions**

All mentors met at least one time with their mentee. A total of 416 logs were submitted by mentors and the mean number of interactions per month was 4.5. Results by month are detailed in Table 11.

According to the contact logs, when meeting in person, the most popular meeting location was the treatment area at 26%, followed by the clinic lobby at 12%. When not meeting in person, participants preferred to meet by phone rather than by email or text.

The length of contacts ranged from 2 minutes to 9.5 hours. The mean length of interaction was 39.14 minutes (SD= 45.96) and the median was 28.5 minutes. Longer interactions were associated with dining out and other more time consuming activities including

grocery shopping and cleaning out a mentee's pantry. See Figure 6 and 7 for detailed stories provided by mentors regarding their interactions with their mentee.

### **Overall Participant Satisfaction**

When asked to rate their overall experience with their mentor, 48% (n=10) of mentees rated their experience as excellent and 38% (n=8) as very good or good. However, 14% (n=3) rated their experience as poor. When asked a similar question, 43% (n=9) of mentors rated their experience with their mentee as excellent and 38% (n=8) as very good or good (Figure 8). As demonstrated in Tables 12 and 13, most mentees and mentors appeared to have been satisfied with the different aspects of the peer relationship they formed. When asked specifically if talking with their mentor encouraged them to think about other treatments for kidney failure, 19 out of 21 (90%) mentees responded affirmatively, with 76% of those citing transplantation as treatment option they are considering. Specific participant quotes are provided in Figure 9.

### **Staff Perceptions and Facility Resources**

Thirty nine staff members were asked complete a survey during the July staff meetings. Thirty seven surveys were completed providing us with a 94.87% response rate. UVA Lynchburg Dialysis has 50 staff members, eleven of which were not considered eligible for the survey because they were hired within the last month and unfamiliar with the *Peer Up!* program (n=7), members of the BioMed Tech or Maintenance team who do not interact with patients (n=3), or members of the Home Dialysis team and do not work with in-center patients (n=1).

As demonstrated in Table 14, when asked about the impact that *Peer Up!* on their job, most staff were indifferent about the program making their job easier; however, most disagreed that it made their job harder or took too much of their time. The staff also perceived the program as beneficial to patients, as shown in Table 15 and Figure 10.

When asked if they had noticed any behavior changes in the patients participating in the program, nearly 73% (n=27) of respondents responded affirmatively. When asked what types of behavior changes they have observed, they cited improved self-management behaviors overall, greater confidence (i.e., patients were more engaged in their own care, more involved, and less fearful); better attendance (patients were coming on time and coming more often/not skipping treatment); positive attitude/mood (i.e., patients seemed calmer, happier, willing to help other patients, and more relaxed); and a noticeable increase in patient-to-patient interaction in the lobby and within the treatment bays.

Program implementation required inputs from the facility, specifically staff and space. Staff was asked to identify required resources, from their perspective, as well as what resources would have been “nice to have.” The themes from their responses are listed in Table 16.

**Table 6: Age by Role***(as of March 1, 2015)*

<b>Age</b>	<b>Mentor Count (%)</b>	<b>Mentee Count (%)</b>
49 or less	6 (26.09%)	7 (30.43%)
50-59	6 (26.09%)	4 (17.39%)
60-69	8 (34.78%)	9 (39.13%)
70-79	1 (4.35%)	3 (13.04%)
80+	2 (8.70%)	0 (0.00%)
Mean	56.74	56.00
SD	15.49	12.85

**Table 7: Years Receiving ESRD Treatment<sup>†</sup>***(as of March 1, 2015)*

	<b>Mentee Count (%)</b>	<b>Mentor Count (%)</b>
≤6 months	7 (30.43%)	n/a
7 months – 1 year	5 (21.74%)	n/a
1 year – 2 years	2 (8.70%)	5 (21.74%)
2 years – 3 years	1 (4.35%)	2 (8.70%)
3 years – 5 years	2 (8.70%)	2 (8.70%)
5 years – 10 years	3 (13.04%)	9 (39.13%)
≥10 years	3 (13.04%)	5 (21.74%)
	<i>(in years)</i>	
<b>Mean</b>	3.82	7.33
<b>SD</b>	5.86	6.55
<b>Median</b>	1.00	6.42

<sup>†</sup>Calculated using CMS Form #2728: ESRD Medical Evidence Report Medicare Entitlement and/or Patient Registration

**Table 8: Demographic Characteristics of *Peer Up!* Participants**  
(as of March 1, 2015)

<b>Demographics</b>	<b>Mentee Count (%) (n=23)</b>	<b>Mentor Count (%) (n=23)</b>
<b>Current Modality</b>		
In-Center Hemodialysis	23 (100%)	21 (91.30%)
Home Hemodialysis	0 (0.00%)	1 (4.35%)
Transplant	0 (0.00%)	1 (4.35%)
<b>Sex</b>		
Female	11 (47.83%)	16 (69.57%)
Male	12 (52.17%)	7 (30.43%)
<b>Race</b>		
African American	21 (91.30%)	17 (73.91%)
Caucasian	2 (8.70%)	5 (21.74%)
More than One Race	0 (0.00%)	1 (4.35%)
<b>Ethnicity</b>		
Not Hispanic or Latino	22 (95.65%)	23 (100.00%)
Hispanic or Latino	1 (4.35%)	0 (0.00%)
<b>Marital Status</b>		
Single/Never Married	7 (30.43%)	9 (39.13%)
Married/Cohabiting	3 (13.04%)	5 (21.74%)
Divorced	4 (17.39%)	2 (8.70%)
Separated	5 (21.74%)	3 (13.04%)
Widowed	4 (17.39%)	4 (17.39%)
<b>Education</b>		
Less than High School	7 (30.43%)	2 (8.70%)
High School Diploma	8 (34.78%)	11 (47.83%)
Some College (No Degree)	4 (17.39%)	3 (13.04%)
Associates Degree (e.g., Cosmetology, LPN, etc.)	2 (8.70%)	1 (4.35%)
More than Associate's Degree (No Bachelor's Degree)	2 (8.70%)	1 (4.35%)
Bachelor's Degree	0 (0.00%)	2 (8.70%)
Some Graduate School (No Degree)	0 (0.00%)	2 (8.70%)
Master's Degree	0 (0.00%)	1 (4.35%)
<b>Employment</b>		
Unemployed	21 (91.30%)	22 (95.65%)
Employed (full-time)	0 (0.00%)	0 (0.00%)
Employed (part-time)	2 (8.70%)	1 (4.35%)
<b>Income</b>		
\$0 - \$19,999	17 (73.91%)	10 (43.48%)
\$20,000 - \$39,999	3 (13.04%)	8 (34.78%)
\$40,000 - \$59,999	1 (4.35%)	1 (4.35%)
\$60,000 - \$79,999	0 (0.00%)	1 (4.35%)
\$80,000 - \$99,999	0 (0.00%)	1 (4.35%)
\$100,000 or more	0 (0.00%)	0 (0.00%)
Don't Know	2 (8.70%)	2 (8.70%)

**Table 9: Mentor Training: Overall Feedback (n=24)**

<b>Item</b>	<b>Strongly Agree Count (%)</b>	<b>Agree Count (%)</b>	<b>Disagree Count (%)</b>	<b>Strongly Disagree Count (%)</b>
1. The trainers/facilitators were well prepared.	22 (91.67%)	2 (8.33%)	0 (0.00%)	0 (0.00%)
2. The handouts were clear and easy to read. <sup>a</sup>	18 (78.26%)	4 (17.39%)	0 (0.00%)	1 (4.35%)
3. The information was useful.	19 (79.17%)	5 (20.83%)	0 (0.00%)	0 (0.00%)
4. The instructions for activities were clear.	21 (87.50%)	3 (12.50%)	0 (0.00%)	0 (0.00%)
5. The role plays allowed me to practice new skills. <sup>b</sup>	15 (75.00%)	5 (25.00%)	0 (0.00%)	0 (0.00%)
6. There was enough time to practice new skills. <sup>c</sup>	15 (71.43%)	4 (19.05%)	2 (9.52%)	0 (0.00%)
7. All my questions were answered.	19 (79.17%)	5 (20.83%)	0 (0.00%)	0 (0.00%)
8. The training was well-organized.	19 (79.17%)	5 (20.83%)	0 (0.00%)	0 (0.00%)
9. The training was scheduled at a convenient time. <sup>a</sup>	16 (69.57%)	7 (30.43%)	0 (0.00%)	0 (0.00%)
10. The training kept my interest.	20 (83.33%)	4 (16.67%)	0 (0.00%)	0 (0.00%)
11. The amount of information covered during the training was appropriate. <sup>a</sup>	17 (73.91%)	6 (26.09%)	0 (0.00%)	0 (0.00%)

<sup>a</sup> n=23, <sup>b</sup> n=20, <sup>c</sup> n=21

**Table 10: Mentor Training: Self-Reported Confidence Level by Task (n=24)**

<b>Item</b>	<b>Totally Confident Count (%)</b>	<b>Somewhat Confident Count (%)</b>	<b>Not Very Confident Count (%)</b>	<b>Not At All Confident Count (%)</b>
1. I can share tips and experience about living with kidney disease.	20 (83.33%)	4 (16.67%)	0 (0.00%)	0 (0.00%)
2. I can name three characteristics of a good mentor. <sup>a</sup>	19 (82.61%)	3 (13.04%)	1 (4.35%)	0 (0.00%)
3. I am able to use my body to show someone I am listening.	21 (87.50%)	3 (12.50%)	0 (0.00%)	0 (0.00%)
4. I am able to respond to someone to show them I heard what they said.	21 (87.50%)	3 (12.50%)	0 (0.00%)	0 (0.00%)
5. I can ask an open-ended question.	21 (87.50%)	3 (12.50%)	0 (0.00%)	0 (0.00%)
6. I can define “stages of change.”	16 (66.67%)	7 (29.17%)	1 (4.17%)	0 (0.00%)
7. I can use praise and encouragement during a conversation.	20 (83.33%)	4 (16.67%)	0 (0.00%)	0 (0.00%)
8. I can lead a <i>Peer Up!</i> meeting/session.	14 (58.33%)	10 (41.67%)	0 (0.00%)	0 (0.00%)
9. I can keep information private. <sup>a</sup>	22 (95.65%)	1 (4.35%)	0 (0.00%)	0 (0.00%)
10. I can set a professional boundary with my mentee.	22 (91.67%)	2 (8.33%)	0 (0.00%)	0 (0.00%)
11. I can ask for help from <i>Peer Up!</i> staff or other mentors.	23 (95.83%)	1 (4.17%)	0 (0.00%)	0 (0.00%)
12. I can keep a conversation on a positive tone. <sup>a</sup>	22 (95.65%)	1 (4.35%)	0 (0.00%)	0 (0.00%)

<sup>a</sup> n=23



**Table 11: *Peer Up!* Meeting Log Summary**  
(Total Number of Peer Pairs = 23)

	March			April		
	Count	Mean	SD	Count	Mean	SD
Contact Logs	84	3.65	2.71	119	5.17	6.42
In-Person Contacts	56	2.43	1.93	58	2.52	2.00
Other Contact†	28	1.22	2.30	61	2.65	6.19
	May			June		
	Count	Mean	SD	Count	Mean	SD
Contact Logs	112	4.87	4.69	101	4.39	5.22
In-Person Contacts	65	2.83	2.32	62	2.70	2.76
Other Contact	47	2.04	5.46	39	1.70	4.04
Intervention Summary						
	Total	Mean		SD		
Contact Logs	416	18.09		17.78		
In-Person Contacts	241	10.48		7.68		
Other Contact	175	7.61		14.06		

†Other contact included phone, email, or text

**Figure 6: Mentee C and Mentor S**

Mentee C was new to dialysis, just starting in February. He knew he was going to have to begin dialysis, but he was still shocked when he actually had to start. Mentor S helped him learn what to expect. Mentor S explained the importance of washing his vascular access before each and every treatment. He also helped Mentee C work with his dietitian to incorporate more protein in his diet. Mentee C was underweight when he began dialysis and has reported gaining weight since starting the program.

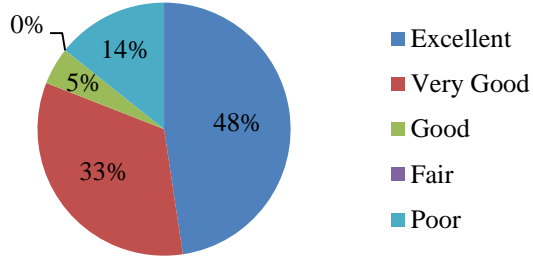
**Figure 7: Mentee R and Mentor G**

Mentee R and Mentor G live in the same apartment building and were paired together because they already had a relationship—Mentor G was helping Mentee R learn to read. Mentor G had been on dialysis for approximately two years, whereas Mentor R had been on dialysis for about seven and half years, but was struggling with his diet and taking his medications. After participating in *Peer Up!*, Mentee R reports that his mentor has taught him how to read food labels. She helped him clean the “junk food” out of his pantry and learn how to make healthier choices while grocery shopping and dining out. Mentor R lost nine pounds during the program and reports he now takes his medication on time and as directed.

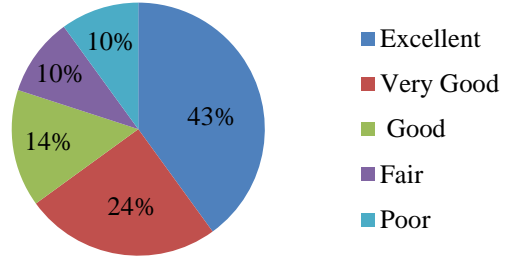
**Figure 8: Overall Participant Experience**

Overall, how would you rate your experience with your mentor/mentee?

**Mentee Response (n=21)**



**Mentor Response (n=21)**



**Figure 9: Participant Quotes from Survey**

“Talking about her problems and mine...I believe we helped each other.”

*Peer Up! Mentee*

“I feel that I was matched with the most appropriate candidate for the type of person I am and am trying to be. I think that it's important that people are matched with people who are similar or dissimilar in a positive way because this, as any other chronic disease, can weigh you down mentally and some people just need a bit of empathy and positivity regarding ESRD.”

*Peer Up! Mentee*

“I really did enjoy the *Peer Up!* Program. Wish I had it when I first started. I think it's great for someone just starting because knowledge is power and to know about your condition is to understand you and what's happening to you and what to expect.”

*Peer Up! Mentor*

“I’ve become more conscious of taking my medicine, controlling my fluids ...and just my overall health. Sometimes, my Mentee became my ...inspiration as well as she made me accountable. We were accountable to each other where our dialysis treatments were concerned...When you have accountability, it helps. You know, because sometimes we don’t just hold our own selves accountable for our day-to-day, every day health...”

*Peer Up! Mentor*

**Table 12: Mentee Program Evaluation (n=22)**

<b>Item</b>	<b>Strongly Agree/Agree Count (%)</b>	<b>Neutral Count (%)</b>	<b>Strongly Disagree/ Disagree Count (%)</b>
1. The talks I had with my mentor were helpful to me.	19 (86.36%)	1 (4.55%)	2 (9.09%)
2. Talking more with my mentor would have been helpful to me. <sup>a</sup>	15 (71.43%)	4 (19.05%)	2 (9.52%)
3. My mentor sharing his or her story was helpful to me. <sup>a</sup>	18 (85.71%)	2 (9.52%)	1 (4.76%)
4. Meeting with my mentor made it easier to cope with my kidney disease.	18 (81.82%)	3 (13.64%)	1 (4.55%)
5. I learned new information from my mentor.	19 (86.36%)	2 (9.09%)	1 (4.55%)
6. I felt comfortable talking to my mentor.	21 (95.45%)	0 (0.00%)	1 (4.55%)
7. I felt comfortable asking my mentor questions.	20 (90.91%)	2 (9.09%)	0 (0.00%)
8. I felt better after talking with my mentor. <sup>a</sup>	19 (90.48%)	2 (9.52%)	0 (0.00%)
9. My mentor listened carefully to me. <sup>a</sup>	19 (90.48%)	2 (9.52%)	0 (0.00%)
10. My mentor was available to me. <sup>a</sup>	18 (85.71%)	3 (14.29%)	0 (0.00%)
11. I would recommend other dialysis patients talk with a mentor like mine. <sup>a</sup>	19 (90.48%)	1 (4.76%)	1 (4.76%)
12. Meeting with my mentor has helped me take better care of myself.	18 (81.82%)	4 (18.18%)	0 (0.00%)

<sup>a</sup>n=21

**Table 13: Mentor Program Evaluation (n=21)**

<b>Item</b>	<b>Strongly Agree/Agree Count (%)</b>	<b>Neutral Count (%)</b>	<b>Strongly Disagree/ Disagree Count (%)</b>
1. The talks I had with my mentee were helpful to me. <sup>a</sup>	17 (85.00%)	3 (15.00%)	0 (0.00%)
2. Working with my mentee helped me feel better.	16 (76.19%)	4 (19.05%)	1 (4.76%)
3. Sharing my story was helpful to me. <sup>a</sup>	18 (90.00%)	1 (5.00%)	1 (5.00%)
4. Meeting with my mentee made it easier for me to cope with my kidney disease.	14 (66.67%)	7 (33.33%)	0 (0.00%)
5. I learned new information from my mentee.	16 (76.19%)	4 (19.05%)	1 (4.76%)
6. Serving as a role model to my mentee made me take better care of myself.	17 (80.95%)	3 (14.29%)	1 (4.76%)
7. I helped my mentee learn to take better care of himself/herself.	18 (85.71%)	3 (14.29%)	0 (0.00%)
8. The mentor training sessions prepared me to be a mentor.	19 (90.48%)	1 (4.76%)	1 (4.76%)
9. I have used what I learned in the mentor training sessions to take care of myself.	18 (85.71%)	2 (9.52%)	1 (4.76%)

<sup>a</sup> n=20

**Table 14: Staff Survey: Impact on Job (n=37)**

<b>Item</b>	<b>Strongly Agree/ Agree Count (%)</b>	<b>Neutral Count (%)</b>	<b>Strongly Disagree/ Disagree Count (%)</b>
1. <i>Peer Up!</i> made my job easier.	14 (37.84%)	22 (59.46%)	1 (2.70%)
2. <i>Peer Up!</i> allowed me to focus more on the daily tasks associated with my role.	14 (37.84%)	20 (54.05%)	3 (8.11%)
3. <i>Peer Up!</i> took too much of my time.	1 (2.70%)	6 (16.22%)	30 (81.08%)
4. <i>Peer Up!</i> made my job more difficult. <sup>a</sup>	1 (2.78%)	4 (11.11%)	31 (86.11%)
5. The <i>Peer Up!</i> program should continue at UVA Lynchburg Dialysis.	34 (91.89%)	3 (8.11%)	0 (0.00%)

<sup>a</sup> n=36

**Figure 10: Staff Quotes from Survey**

“...The coolest thing was the day I saw a pair throwing a football out beside the dialysis unit - simple fun for a dialysis [patient] - we don't get to see that often enough. The caring attitude of some of the mentors and their ongoing involvement with their mentee is amazing - and the lengths some have gone to help others. I think we need this program, not just here, but throughout dialysis everywhere - what a great way to improve patient engagement and provide a caring resource that totally knows what you are feeling the first few times you come through the door. THANK YOU!”

“I spoke with a patient (mentee/mentor) who was paired with another patient. Neither patients had an outlet and never went anywhere. I could tell a big difference in the mood of my patient. She and her mentor/mentee talked all the time and went to eat together. I was very touched by this.”

**Table 15: Staff Perceptions of Patient Benefits (n=37)**

<b>Item</b>	<b>Strongly Agree/ Agree Count (%)</b>	<b>Neutral Count (%)</b>	<b>Strongly Disagree/ Disagree Count (%)</b>
1. <i>Peer Up!</i> helped the patients who participated in it.	33 (89.19%)	4 (10.81%)	0 (0.00%)
2. The patients participating in <i>Peer Up!</i> seemed to enjoy the program.	36 (97.30%)	1 (2.70%)	0 (0.00%)
3. The patients participating in <i>Peer Up!</i> seemed glad they participated.	37 (100.00%)	0 (0.00%)	0 (0.00%)
4. Patients participating in <i>Peer Up!</i> were satisfied.	34 (91.89%)	3 (8.11%)	0 (0.00%)
5. I encouraged patients to participate in the <i>Peer Up!</i> program.	36 (97.30%)	0 (0.00%)	1 (2.70%)
6. <i>Peer Up!</i> created a sense of camaraderie among patients.	34 (91.89%)	3 (8.11%)	0 (0.00%)
7. Participating in <i>Peer Up!</i> would benefit other patients at UVA Lynchburg Dialysis.	35 (94.59%)	2 (5.41%)	0 (0.00%)

**Table 16: Staff and Facility Resources Required**

<i>Staff</i>	<i>Space</i>
<ul style="list-style-type: none"> <li>- Information/nominations for program</li> <li>- Input from social workers and nurses to form pairs</li> <li>- All diet-related materials reviewed by dietitians</li> <li>- Menus for mixers and mentor trainings approved by and/or suggested by dietitians</li> </ul>	<ul style="list-style-type: none"> <li>- Meeting space for trainings and social mixers</li> <li>- Semi-private meeting space for peer pairs in lobby</li> <li>- Corner of conference room became “make-shift” <i>Peer Up!</i> Office/storage area</li> </ul>
<b>“Nice to Have”</b>	
<ul style="list-style-type: none"> <li>- More staff dedicated to program</li> <li>- More staff directly involved with program</li> </ul>	<ul style="list-style-type: none"> <li>- Dedicated, private room for peers to meet</li> <li>- Computer for patients to use</li> </ul>

## Aim 2

To evaluate the impact of the 4-month P2P program on psychosocial health indicators.

Results for mentees' measures meeting both parametric and nonparametric test criteria are provided in Table 17. *Peer Up!* had a statistically significant impact on many of the psychosocial variables examined. Repeated measures one-way ANOVAs (within subjects) demonstrated significant increases between the means for self-efficacy,  $F(2,22)=8.15, p<.01$ ; knowledge,  $F(2,44)=6.62, p<.01$ ; perceived social support,  $F(2,22)=7.30, p<.01$ ; and dialysis social support,  $F(2,44)=4.79, p=.01$ . The nonparametric Friedman's test showed a statistically significant increase in health-related quality of life,  $\chi^2(2) = 12.46, p<.01$ .

**Table 17: Comparison of Psychosocial Measures across Time Periods, Mentees (n=23)**

Measures	Baseline		Interim		Final		<i>p</i> -value
	Mean	SD	Mean	SD	Mean	SD	
<b>Repeated Measures ANOVA (Parametric)</b>							
Self-Efficacy	7.29	2.10	7.65	1.83	8.31	1.45	<.01
Knowledge	13.22	3.67	14.87	4.16	15.87	3.84	<.01
Perceived Social Support	3.84	0.99	4.15	0.94	4.32	0.79	<.01
Dialysis Social Support	2.17	1.18	2.60	1.11	3.12	0.98	.01
<b>Friedman's Test (Nonparametric)</b>	<b>Median</b>	<b>IQR</b>	<b>Median</b>	<b>IQR</b>	<b>Median</b>	<b>IQR</b>	<b><i>p</i>-value</b>
Health-Related Quality of Life <sup>a</sup>	4.00	1.00	3.00	1.00	3.00	2.00	<.01
Dialysis Self-Management	3.33 <sup>b</sup>	0.50	3.50	0.50	3.67	0.34	.09

<sup>a</sup>Scale: Excellent=1; Very Good=2; Good=3; Fair=4; Poor=5

<sup>b</sup>n=22

It was hypothesized that mentees who had a CVC only would report greater intention to consult with a vascular surgeon to have an AVF or AVG placed over the course of the program. Three participants entered the program with only a CVC. When asked about their intentions to consult with a vascular surgeon at the three time points of the program, all three showed movement along the continuum 1) from not ready to schedule an appointment to already scheduled an appointment 2) from planning to schedule an appointment to attended an

appointment, and 3) from already scheduled an appointment to having an AVF placed. Figure 11 highlights the question from the instrument used to gauge participations' intentions. Figure 12 highlights a story, as shared by a mentor, relating to her and her mentee's discussions related to AVF.

#### **Figure 11: Intention to obtain an AVF or AVG**

Thinking about the vascular access you use for dialysis, would you say that you...

- Are not ready to schedule an appointment with a doctor about placing an AV fistula or graft in the next 3 month
- Are thinking of scheduling an appointment with a doctor about placing an AV fistula or graft in the next 3 months
- Are planning to schedule an appointment with a doctor about placing an AV fistula or graft in the next month
- Have already scheduled an appointment with a doctor about placing an AV fistula or graft
- Have attended an appointment with a doctor about placing an AV fistula or graft
- Have an AVF placed but it is not useable at this time
- Don't know

#### **Figure 12: Mentee G and Mentor B**

Mentee G began dialysis about a week before the *Peer Up!* program began. He started dialysis with a CVC and stated that he did not know anything about dialysis. He was paired with Mentor B, a former nurse, and dialysis patient since 2007. She was able to answer many of his questions and talked to Mentee G about the importance of getting an AVF. During one of their meetings, she rolled up her sleeve and showed Mentee G her access. She allowed him to touch it and feel the thrill. Since that meeting, Mentee G reports he has had a consultation with a vascular surgeon, completed vein mapping, and plans to schedule surgery.

### **Aim 3**

To evaluate the impact of the 4-month P2P program on mentors' psychosocial health indicators.

*Peer Up!* also had a statistically significant impact on some of psychosocial variables examined among mentors, as shown in Table 18. A repeated measures one way ANOVA (within subjects) demonstrated a significant increase between the means for knowledge,  $F(2,22)=11.88$ ,  $p<.01$  and dialysis social support,  $F(2,42)=3.19$ ,  $p=.05$ . A comparison of the repeated measures



performed using Friedman’s test showed a statistically significant increase in dialysis self-management,  $\chi^2(2) = 7.65, p = .02$ .

**Table 18: Comparison of Psychosocial Measures across Time Periods, Mentors (n=23)**

Measures	Baseline		Interim		Final		p-value
	Mean	SD	Mean	SD	Mean	SD	
<b>Repeated Measures ANOVA (Parametric)</b>							
Self-Efficacy	8.36	1.53	8.33	1.69	8.11	1.60	<b>.60</b>
Knowledge	15.96	4.31	17.74	3.05	18.35	3.56	<b>&lt;.01</b>
Perceived Social Support	3.82 <sup>a</sup>	0.76	4.18 <sup>a</sup>	0.84	3.83	0.86	<b>.60</b>
Dialysis Social Support	3.00 <sup>a</sup>	0.89	3.09 <sup>a</sup>	0.91	3.34	0.89	<b>.05</b>
<b>Friedman’s Test (Nonparametric)</b>	<b>Median</b>	<b>IQR</b>	<b>Median</b>	<b>IQR</b>	<b>Median</b>	<b>IQR</b>	<b>p-value</b>
Health-Related Quality of Life <sup>b</sup>	3.00	1.00	3.00 <sup>a</sup>	0.00	3.00	0.0	.33
Dialysis Self-Management	3.43 <sup>a</sup>	0.83	3.57 <sup>a</sup>	0.43	3.71 <sup>a</sup>	0.43	<b>.02</b>

<sup>a</sup>n=22

<sup>b</sup>Scale: Excellent=1; Very Good=2; Good=3; Fair=4; Poor=5

## **Chapter 5: Discussion**

This study demonstrates that peer mentoring implemented among in-center hemodialysis patients may be beneficial for *both* mentees and mentors and adds to the growing body of literature examining peer mentoring as an intervention in chronic disease. Mentees reported improved self-efficacy, increased knowledge, higher perceived social support, and increased dialysis social support. Mentors benefited as well, reporting improved dialysis self-management behaviors, increases in knowledge, and increased dialysis social support. To this end, this chapter will interpret the findings of this study within the larger context of the peer mentoring literature. Several expected and unexpected factors were identified that influenced the implementation and outcomes of the *Peer Up!* intervention. These included program appeal, program processes for identifying and training mentors, pairing mentors and mentees and involvement of facility staff and resources. The role of these factors will be discussed in detail and the chapter will conclude with a discussion of program sustainability and replication in other dialysis facilities and chronic disease settings.

### **Effects of Peer Mentoring on Mentees**

This study contributes to the extant peer mentoring literature in that it is the first study with in-center hemodialysis patients to show improved self-efficacy, increased knowledge, higher perceived social support, and increased dialysis social support amongst mentees. Approximately 52% of the mentees in this study had been on dialysis a year or less, were facing the tremendous challenge of managing ESRD in the early stages when there is so much to learn, and attempting to adjust to a life changing diagnosis that is often associated with

profound feelings of grief and loss.<sup>110</sup> Given the high 90-day and first-year mortality rates observed in hemodialysis patients, these findings are encouraging because they indicate that a peer mentoring intervention may help patients adjust and cope, and may be especially helpful to newer patients.<sup>2,98,111</sup> These findings are consistent with the peer mentoring literature in diabetes, which showed mentees experienced increased knowledge and social support.<sup>62,65</sup> Peer mentoring has also been shown to be more successful among patients with diabetes who have lower self-management or are considered high risk, like patients new to dialysis.<sup>112</sup> However, the diabetes peer mentoring programs also demonstrated improvements in HbA1c, whereas the mentees in this study did not report improved dialysis self-management (i.e., adherence to fluid and dietary restrictions, medication regimen, and in-center dialysis prescription).<sup>62-64</sup> It is surprising that mentees did not report improved dialysis self-management behaviors given that self-efficacy positively correlates with chronic disease self-management, knowledge is an important construct to address in self-management intervention (i.e., cognitive component), and social support has been shown to predict survival among patients on hemodialysis.<sup>31,60,79,80,91</sup> Consistent with social cognitive theory, increases in these constructs (i.e., self-efficacy, social support, and knowledge) can influence health behavior, and therefore, ultimately should improve self-management, but it may not have occurred in this study because these behaviors may take longer to improve. The diabetes peer mentoring programs demonstrating improvements in HbA1c were six months whereas *Peer Up!* was four months. Thus, a longer intervention period may have resulted in improved dialysis self-management behaviors and this is a consideration for additional testing and research. Response bias related to dialysis self-management behaviors is also possible. Participants self-reported behaviors were used for analysis. A similar clinical marker to HbA1c that is somewhat objective and indicates overall

self-management does not exist in hemodialysis. Participants, either knowingly or unknowingly, may have reported that they were doing a better job at their dialysis self-management behaviors initially than they were. Their average scores on a 4-point scale were high at baseline and perhaps experienced a ceiling effect.

It is important to note that the knowledge improvement among the mentees may have resulted from their interactions with their mentor. Unlike mentors, mentees received no formal training and did not participate in any educational sessions. The kick-off mixers held at the beginning of the intervention served to introduce all participants to the structure of the program, like the recommended number of times to meet and general ground rules. Similarly, the celebration mixer served to recognize participants' completion of the program and close of the intervention. None of these events provided any educational information to mentees. Further, the facility did not have any other facility-wide initiatives in process that could have increased knowledge. The information and knowledge that was acquired could have occurred from mentors sharing the information they learned in the training and booster sessions and sharing their own personal stories and experiences. Participants may have sought information from other sources, either as a result of the intervention or on their own. Information regarding information seeking behavior was not captured as part of this evaluation, but could have impacted participants' knowledge. Further, while the peer logs captured general information regarding mentor-mentee interactions, more research is needed to fully understand the information exchanged and how this may increase knowledge; however, this may prove challenging to obtain as peer reporting can vary both in frequency and details and there is an element of privacy that is necessary for the peer relationship to function well.

## Effects of Peer Mentoring on Mentors

Mentors are an essential element in a peer mentoring program, but they also reap benefits. *Peer Up!* was associated with improved scores in three psychosocial measures among mentors—knowledge, dialysis social support, and dialysis self-management. These findings contribute to the literature in that it is one of the few peer mentoring studies to examine the effects of the intervention on mentors. The mentors received seven hours of training therefore it is not surprising that knowledge would increase. Further, it is widely accepted that teaching or explaining something to others helps the teacher learn as well.<sup>113,114</sup> It is possible that sharing the knowledge and information learned during the training and booster sessions with mentees helped the mentors increase their own knowledge. Dialysis social support and dialysis self-management behaviors both increased significantly, but nothing within the *Peer Up!* intervention explicitly focused on these constructs for mentors. In fact, it was hypothesized that mentors' reported dialysis self-management behaviors would remain consistent, rather than improve. It was conjectured that mentors were already performing dialysis self-management behaviors at a high level of consistency and the program would merely reinforce the consistency, thus a ceiling effect was anticipated. However, the mean dialysis self-management scores at baseline between mentors (3.43) and mentees (3.33) were similar. Further, given that providing support to others has been shown to help oneself, these increases should have been anticipated.<sup>18,115</sup> The limited research available examining effects on peer mentors indicates that mentors report higher levels of confidence, self-awareness and self-esteem as well as improvements in depression and role functioning.<sup>115</sup> Further, emerging research suggests that providing support to others actually impacts neural mechanisms in the brain of the support giver by "...reducing activity in stress and threat-related levels during stressful experiences..." and thereby may benefit the giver of support

more than the receiver.<sup>116</sup> In this study, the increase in the mean scores related to the social support measure may also relate to meeting other mentors during the training and booster sessions. Mentors commented that they enjoyed learning new things with fellow mentors outside of the treatment setting. Finally, the improvement in dialysis self-management behaviors may relate to mentor feeling accountable to their mentees. Mentors expressed feeling that they felt they had to “do good” because they were role models for their mentees. Mentors also mentioned that they learned from their mentees as well. This is consistent with finding of Sandhu et al. indicating that peer mentors learned from “...mentees fortitude and self-management skills.”<sup>67</sup>

### **Considerations for Implementation**

#### **Patient Participation**

This study indicates that peer mentoring is a viable intervention for in-center hemodialysis patients to address dialysis self-management behaviors and adherence. Patients are willing to pair with a peer, as either a mentee or mentor, and participate in a peer-to-peer relationship to help themselves and fellow patients. Pairing patients together to discuss their shared experience was valuable to both mentees and mentors. Meeting and talking to another patient may provide insight and vicarious experience that patients are unable to receive in any other formalized way or from medical providers.

Both mentees and mentors enjoyed participating in the program and benefited from giving as well as receiving social support. Social support may alleviate some of the isolation and fear that patients may experience, particularly patients who are newly diagnosed. Participants in this study reported their overall experience with their mentor/mentee as positive with 44% of mentees expressing interest in becoming mentors and 74% of mentors expressing interest in remaining involved with a peer mentoring program as either a mentor or advisor (i.e.,

participating in training of new mentors, offering technical assistance to new mentors, and participating in committee to sustain the program). Further, it is estimated that approximately 25% of the *Peer Up!* pairs continued to meet after the completion of the program because they liked the socialization and enjoyed the relationship they had developed with another patient at the facility.

### **Identifying Mentors**

It is clear that mentors contribute to the success of any peer mentoring program and may be the most important component. Facility staff identified and nominated mentors for the *Peer Up!* program. Staff nominated any patient who they thought could help a fellow patient by sharing their story and serving as a leader. Beyond the eligibility requirements detailed in the Methods section of this document, staff were also encouraged to nominate patients who were outgoing and actively engaged in their own care. In some cases, mentors learned about non-adherence in the most challenging way, by not following recommendations and being hospitalized or nearly dying. They wanted to share their experiences with other patients so that they did not experience the same challenges. Others fully followed their health care recommendations and never had any issues or hospitalizations related to dialysis non-adherence. Although this information was not used to pair mentors with mentees, it is important to not disqualify patients that have struggled with adherence in the past from serving as mentors. Some mentees appeared to do well with mentors that had not always been adherent, because these mentors seemed “real” and they struggled in the beginning just as they were now. Other mentees did well with mentors that just followed the recommendations from the beginning because they approached their “new normal” in a very practical way and were able to talk about how to

incorporate the new tasks or self-care behaviors into their lives. Both types of mentors have valuable experiences to share and may help mentees.

Research has suggested that mentors with lower self-efficacy in diabetes management, higher levels of diabetes distress, and depression are more successful as mentors because their own uncertainty can foster improved self-management.<sup>117</sup> This was not the experience in this study. A facility social worker nominated a long-time patient that was struggling with dialysis self-management thinking that the program might be the incentive she needed to take better care of herself. While some mentors stated that they struggle with the day-to-day challenges of self-management, this was the only individual nominated to be a mentor specifically because she had self-management problems. This individual was not successful as a mentor and it ultimately seems unfair to the mentee. The mentor appeared to benefit from the training and other program activities, as indicated by her responses on the survey instruments but she did not meet with her mentee the recommended number of times and was unresponsive when contacted. While it may be tempting to include long-time patients that are struggling as mentors, with the hope that they will help themselves while helping someone else, it may ultimately be a disservice to both the mentor and mentee. It is best to include any patient interested participating, but is struggling with adherence, as mentees.

### **Training Mentors**

The mentor training and training booster were critical to the success of the intervention. Training must teach mentors to tell their story in a way so that it is helpful and not perceived as medical advice. At first, mentors were somewhat hesitant to commit to or attend a 5-hour training, particularly when it was described as including training on how to communicate or talk to one another. However, once they attended, many of them commented on how much they



enjoyed being with other patients in a non-dialysis setting and how much they learned. When it was time to schedule the booster trainings, the best days and times were elicited from mentors. Many expressed their excitement to meet again and some even responded by stating, “just let me know when and where.”

The booster training offered a unique opportunity to check in with the mentors to see how their relationships and interactions were going. Mentors shared their stories about what worked well in connecting with their mentees and what did not work so well. The group brainstormed ways to help if a mentor had a problem reaching his mentee. This sharing of experiences helped mentors that were struggling to make a connection with their mentees and provided them with new ways to approach their mentees. The mentors were essentially mentoring each other and problem-solving ways to overcome mentoring challenges in ways that made sense to them, as mentors and patients, not from a professional or clinician point of view. For example, the most successful mentors suggested that mentors continue to follow up with their mentees even if they were being non-responsive. Some discussed how they took it upon themselves to meet with their mentees while they were dialyzing because they knew that they could not be ignored or avoided during that time. These mentors talked about how they struggled when they first started dialysis and that they would have likely done the same thing to a mentor, so that was why they wanted to try harder to help. They reinforced the idea that a mentor should not take a mentee’s behavior personally, but rather try to empathize and approach in a different way. This was an unanticipated finding, but wholly demonstrates the mentors’ commitment to the program and willingness to try different approaches to make it work. Thus, training boosters should be incorporated as a formal program component as they serve as an organic forum for group

problem solving and an important opportunity for mentors to receive peer support from each other.

### **Pairing Mentors and Mentees**

Pairing patients together in a mutually supportive relationship is essential to the success of the pair and to the program; however, there is no specific algorithm or checklist available to create successful pairs. Transportation is a significant barrier for in-center hemodialysis patients and as such, pairing patients with limited transportation but similar treatment times made sense logistically. Beyond that, *Peer Up!* attempted to achieve congruence within pairs by race, gender, and age. This is supported in the peer mentoring literature and by Social Cognitive Theory, which suggests that vicarious learning occurs best when the mentee sees himself as similar to the mentor.<sup>62-64,69,117</sup> However, operationalizing those recommendations was not always possible. Further, this work suggests that these may not be critical to successful pairing in this patient population for several reasons. The patient population in a particular facility may be relatively homogenous because it is drawing from a specific community or geographic location, so pairing on merely demographic characteristics is not enough. Further, the individuals who participate in the program ultimately limit pairing options. *Peer Up!* had more women than men participate as mentors so pairing by gender was not an option in all cases. Transportation barriers further limited the pairing process because only certain participants were available for pairing with others because their treatment times overlapped. This study demonstrates that it is more important to know the patients in the program and try to match them on their personality characteristics. For instance, pairing a shy or introverted mentee with a quieter, reserved mentor will likely not be beneficial because neither may be comfortable taking the lead or initiating an interaction. Some of the demographically non-concordant pairs in this study were the most

successful in that they met most or spent the most time together. Their similarities included attending the same church, living in the same apartment building, and friendly, outgoing personalities.

Pairing based on treatment time is beneficial because it helps to create accountability within the pair and it became part of the treatment process. As with any intervention, individuals may decide to sign up, but not actually participate. This may be especially true in this population because they are very ill and may be dealing with a myriad of stressors, including loss of employment, struggling to meet basic needs (e.g., shelter, transportation, etc.), social isolation, and fear of death.<sup>12-14,110</sup> They may not want to meet with their peer, even though this may be the time that the relationship would be the most helpful. Knowing that they would see each other during treatment appeared to make participants more receptive to meeting around their treatment time. It made it more difficult for one individual in the pair to ignore the messages or attempts to interact by the other individual. Further, some dyads would meet while one individual was dialyzing. This afforded the mentee with a very rich interaction as the mentor could explain what the machine was doing, why it might alarm, and provided an opportunity to involve the dialysis technicians and other floor staff in the mentoring program as they could interact with the dyad and answer any questions. Meeting during treatment times made it easier for participants to participate. Patients did not have to go somewhere or do yet another thing to participate. It occurred during their time at the facility and did not require additional effort.

Pairing participants together comes with its own unique challenges and much of depends on the personalities of the participants. The facility staff person pairing participants together must ask for input from other staff members, particularly the dialysis technicians/patient care technicians and other floor staff. These staff members spend the most amount of time with the

patients and therefore tend to know them and their personalities well. They can provide anecdotal suggestions for pairings within the same shift or across different shifts, if transportation is not an issue. Further, if a pair is not thriving, it may be necessary to re-assign participants, which may be more challenging the longer the program goes on and others have established their relationships.

Participant re-assignment was necessary during the *Peer Up!* program because one pair was not connecting. Rather than re-assigning the mentee to another mentor, she asked to work with the patient consultant. As indicated earlier, *Peer Up!* used a patient consultant to help implement the program. This individual was a transplant recipient that formerly dialyzed at UVA Lynchburg. Formally trained as a social worker, the consultant assisted with pairing individuals together and worked with each of the pairs to encourage them to meet and interact. The mentee that requested she work with her required significantly more assistance than her assigned mentor was able or willing to provide. This is not an opportunity that would be available to all facilities implementing a peer mentoring program nor is it necessary that each mentor have the skills of a trained social worker. However, while the consultant was encouraging the pair to meet and interact, the mentee started to form a relationship with her and, in the meantime, was not forming a relationship with her assigned mentor. While the mentor decided to quit the program rather than work with another mentee, using the consultant as a mentor enabled the program to serve the mentee rather than her also dropping out. Thus, some relationships are hard to predict and individuals implementing a peer mentoring program may find themselves in situations where pairings do not work, but patients still require the social support and knowledge. Problem solving is necessary, and while the solution may not be exactly what was anticipated, it may help to make the situation workable for most, if not all, of the participants.

## **Dialysis Facility and Staff Roles**

The setting for this study was a large dialysis facility in western Virginia. The facility staff assisted with the implementation by providing feedback and guidance, but were not directly involved with program implementation. The facility administrator or a charge nurse approved use of facility resources, including meeting space, lobby bulletin boards, and lobby television monitors. Every effort was made to include the facility staff in the program, but most were too busy to assist beyond a superficial level. This is likely a significant contributing factor as to why the program has not continued after the pilot.

A toolkit was developed to help dialysis facilities implement the *Peer Up!* program. The toolkit (<http://www.esrdnet5.org/Peer-Up!-Program-Toolkit.aspx>) includes all of the materials used in this program, including program management guidance, the mentor training curriculum, and evaluation instruments. The toolkit also includes a presentation and talking points for facility staff to use with leadership, including the medical director, to obtain buy-in and approval to launch a similar program.

It is critically important for an internal staff person to lead the program and be responsible for launching it; however, a small implementation committee should be formed, involving members from interdisciplinary care team (i.e., dietitians, social workers, nurses, and dialysis care technicians). All facility staff should be aware of the program. *Peer Up!* sought guidance from social workers, nurses, dialysis technicians, and dietitians. Each contributed information and feedback to the program. For example, social workers, technicians, and nurses provided information regarding which individuals might work well together, dietitians and nurses reviewed patient education materials, and dietitians approved menus for trainings and mixers. Including all staff helps patients see the facility's commitment to the program and patient

care. Staff can inquire with patients to see how the program is going. Further, if a problem occurs during implementation, staff are aware of program and can inform the program leadership in a timely fashion.

Implementing a peer mentoring program requires a significant amount of time; however, it may save time in the long-term as patients feel better and experience improved outcomes. Facility staff reported that patients in the *Peer Up!* program appeared calmer, happier, and to have more confidence. Happier patients require less intensive care, experience better outcomes, and live longer.<sup>118</sup> Thus, while implementing a peer mentoring program may not seem like delivering medical care, its outcomes may be just as influential and worth the time investment. Further, once a peer mentoring program is implemented and a cadre of trained mentors exists, they may slowly begin to take a larger leadership role in the program and reduce some of the time required by the facility staff to operate the program. For example, experienced mentors can train new mentors and provide technical assistance.

### **Areas for Additional Inquiry**

This was a pilot study to determine if peer mentoring was feasible and could potentially impact dialysis self-management behaviors. The findings of this study are encouraging and begin to build a foundation for further inquiry. Although not adequately powered to draw conclusions, sub-group analyses were conducted to generate additional hypotheses for research, including length of time on dialysis and health-related quality of life, and marital status and social support.

### **Length of Time on Dialysis and Health-Related Quality of Life**

It has been suggested that peer mentors can help new patients by alleviating fears and helping them adapt to their diagnosis.<sup>15</sup> Additionally, a pilot study conducted with patients newly diagnosed with inflammatory arthritis (i.e., disease duration six to 52 weeks) suggested mentees experienced improvements health-related quality of life.<sup>67</sup> The *Peer Up!* program was

not limited to new patients, but 12 of the 23 mentees, or 52%, were categorized as new patients (i.e., receiving dialysis for one year or less.) A sub-group analysis comparing health-related quality of life for established mentees (i.e., those receiving dialysis more than one year) to that of new mentees (i.e., those receiving dialysis for one year or less) suggests that new patients may benefit from this type of program more than established patients, as their health-related quality of life increased,  $\chi^2(2)=10.47, p<.01$  (Table 19). As noted previously, mortality rates tend to be the highest within the first 90 days and first year of hemodialysis treatment and so additional inquiry should examine if new patients might benefit more than existing patients. Should the hypothesis that new patients benefit more than established patients be found to be true, this may help facilities with limited resources target new patients for participation.

**Table 19: Comparison of Health-Related Quality of Life by Time on Dialysis, Mentees<sup>†</sup>**

Sub-group Friedman's Test	Baseline		Interim		Final		p-value
	Median	IQR	Median	IQR	Median	IQR	
Dialysis, ≤1 year (n=12)	3.50	1.00	3.00	1.50	2.50	1.5	<.01
Dialysis, >1 year (n=11)	4.00	1.00	3.00	1.00	3.00	1.00	.24

HRQoL Scale: Excellent=1; Very Good=2; Good=3; Fair=4; Poor=5

<sup>†</sup>Sample size is less than number determined by power calculation

### **Marital Status and Perceived Social Support**

As noted previously, perceived social support increased amongst mentees. This could be because a majority of the mentees (n=20) were non-married (i.e., single/never married, widowed, divorced, or separated). It is possible that these individuals may not have much social support. A sub-group analysis examining perceived social support among non-married mentees suggests that non-married individuals may benefit from this type of program,  $F(2,19)=4.72, p=.02$  (Table 20). The sample size was too small (n=3) to conduct a similar analysis for married mentees. Participants were not asked about their household composition so it is unclear if these

patients had social support within their household from other family members (i.e., someone other than a spouse or significant other) despite not being married or cohabiting. Thus, additional research should seek to explore the role of social support networks and if those lacking social support in their home environment may benefit more, as compared to those with strong social support networks, from a P2P program. Are individuals lacking social support drawn to a P2P program for social support? Further, how does the quality of social support impact participation and outcomes? For example, it has been shown that not all social support is helpful and so a greater understanding of the quality of social support received from others and how that may influence participation and outcomes in a P2P program is warranted.<sup>36,38</sup>

**Table 20: Comparison of Perceived Social Support by Marriage, Mentees<sup>†</sup>**

Measures	Baseline		Interim		Final		<i>p</i> -value
	Mean	SD	Mean	SD	Mean	SD	
<b>Repeated Measures ANOVA</b>							
Non-Married (n=20)	3.93	0.97	4.17	0.95	4.36	0.78	<b>.02</b>
Married (n=3)	3.21	1.08	4.04	1.00	4.01	.93	<b>--*</b>

*\*Repeated Measures ANOVA not conducted due to small sample size*

<sup>†</sup>Sample size is less than number determined by power calculation

Perceived social support was unchanged among mentors. However, similar to the mentees, a majority were non-married (n=18). A sub-group analysis examining perceived social support among non-marital mentors was not significant (Table 21). Comparing means across the time periods between mentors (Table 21) and mentees (Table 20), the means were slightly lower across all time periods. Additional research is needed to understand this phenomenon. Again, participants were not asked about their household composition so it is unclear if these patients had social support within their household.



**Table 21: Comparison of Perceived Social Support by Marriage, Mentors<sup>†</sup>**

Measures	Baseline		Interim		Final		<i>p</i> -value
	Mean	SD	Mean	SD	Mean	SD	
<b>Repeated Measures ANOVA</b>							
Non-Married (n=18)	3.81 <sup>a</sup>	0.76	4.07 <sup>a</sup>	0.88	3.91	0.81	.26
Married (n=5)	3.85	0.86	4.55	0.58	3.55	1.08	--*

<sup>a</sup>n=17

\*Repeated Measures ANOVA not conducted due to small sample size

<sup>†</sup>Sample size is less than number determined by power calculation

### Limitations/Threats to Validity

While steps were taken to limit threats to validity, this study had limitations. One study site was chosen to determine program feasibility, but also due to limited resources and as such, external validity is limited. The population of patients treated at site is from rural areas and of low socioeconomic status. While rural populations tend to be underrepresented in research, the experience at this facility may not be replicable at a facility in an urban setting due to different culture and environmental norms. Further, it could be argued that every dialysis facility has its own unique patient culture and conditions, and a program such as *Peer Up!* is not needed or would not produce similar results; however, the demographics and psychosocial characteristics of the participants in this study are similar to those in the U.S. dialysis population. Threats to internal validity, including small sample size, selection bias, response bias, maturation bias, and attrition cannot be ruled out as a control or comparison group was not available.

### Small Sample Size and Post Hoc Analyses

Although adequately powered to detect a change within subjects, the sample was not large enough to conduct post hoc analyses (i.e., Bonferroni Procedure) to determine the exact time periods when the changes occurred.

## **Selection Bias**

Patients are a critical resource. For example, the ESRD P2P programs identified through the literature search and environmental scan had a variety of formats, at various levels (e.g., facility-level, regional, or geographic-level, or independent of any facility); however, nearly all shared the patient's active involvement, many from program inception. Patients bring intangible resources, such as enthusiasm, motivation, and commitment, which are paramount for a program's success and sustainability, but these patients may differ from the rest of the patient population. Thus, patients who elect to participate may differ from those who choose not to do so. It is quite possible that patients who participate tend to be more engaged and motivated in their own care and treatment than other patients; conversely, some patients who need the program the most may be the very individuals that do not participate.

Asking staff to nominate mentors and mentees for the program was one way to address selection bias and it may have brought some individuals into the program that would not have participated otherwise. For example, some mentors mentioned that they felt honored and almost a responsibility to the facility to participate because they were nominated. Conversely, it could be argued that staff nominated their "favorite" patients for the program and thus the sample is biased. This seems unlikely given that patients were also free to volunteer for the program and did not have to be nominated by staff. Staff nominations were just one tactic used for recruitment. Further, nearly 20% of the in-center patient population participated in the program and so it is unlikely that all of those patients were staff "favorites."

## **Response Bias**

It is possible that response bias may have occurred either knowingly or unknowingly. Paper/pencil surveys and self-report forms (i.e., interaction logs) were used as data collection

instruments. It is possible that participants may have reported or perceived themselves as doing better with regards to certain outcomes. For example, participants may have reported themselves as doing better with their self-management tasks. This may be why no statistically significant changes were observed among the mentees regarding their self-management tasks despite having significant changes in all of the other outcomes. Future research could examine how self-reported self-management may correlate to clinical values, such as fluid gain between dialysis treatments, serum phosphorus levels, and treatment attendance. Further, participants were aware that this intervention was being evaluated and that could have influenced their responses on the data collection instruments.

### **Maturation Bias**

Twelve of the 23 mentees in the study had been on dialysis a year or less and four of those individuals started dialysis within 30 days of the launch of the intervention. It is possible that patients learned more on their own and “matured” in their new role as a person receiving dialysis treatment. For example, the sub-group analysis examining health-related quality of life for established mentees (i.e., those receiving dialysis more than one year) to new mentees (i.e., those receiving dialysis for one year or less) suggests that new patients may benefit from this type of program more than established patients; however, more research is needed to understand if that is related to the new patients simply maturing and adjusting to their treatment regimen or related to the intervention itself.

### **Attrition**

Attrition was anticipated since these patients have significant co-morbidities and high symptom burden. However, this study had a 93.5% (43/46) completion rate, with two unable and one unwilling to complete the intervention. This did not impact statistical power.

## **Chapter 6: Conclusion**

A peer mentoring program for in-center hemodialysis patients may be largely beneficial for both mentees and mentors, even when conducted on a pilot basis over a short period of time. Mentees experienced improvements in self-efficacy, knowledge, social support, and dialysis social support; however, a decrease in quality of life was observed and this warrants further research to better understand. Mentors experienced improvements in knowledge, dialysis social support, and self-management.

This program was successful, in part, because it used one of the most underutilized resources within the health care system—patients. Patients may help each other in a way that health care providers may not be able to, by sharing lived experiences and support. The participants in this study were committed to the program and enjoyed helping each other. This is further supported by anecdotal evidence that some peer pairs were still in contact or meeting after the intervention.

The evaluation of this intervention starts to fill the void observed in the extant literature related to peer mentoring within the in-center hemodialysis setting. It begins to build on the limited evidence available within ESRD for using peers to increase self-management behaviors and provide support. Future efforts should focus on programs extending over longer time periods with larger groups of patients and employing more rigorous research designs. These might include testing the program at multiple sites across the country, both rural and urban locations, and ultimately conducting randomized controlled trials. Longitudinal studies could also be conducted to determine if peer mentoring affords benefits beyond the intervention period.

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## **Appendix A Environmental Scan within Dialysis Community**

### **Introduction**

Little has been published on ESRD-focused adult peer support programs. An environmental scan with subsequent key informant interviews was conducted in July 2014 to identify ESRD-focused peer support programs that exist at the community level, but may not be published in the extant literature. These findings were used to inform the implementation and evaluation of a peer mentoring to increase dialysis self-management behaviors among in-center dialysis patients.

### **Methods**

An online environmental scan instrument, consisting of approximately 18 questions, was developed to identify individuals who may have experience with peer programs in the ESRD community.

The PI collaborated with the ESRD Network that is responsible for the state of Virginia and is based in Richmond, Virginia. The Mid-Atlantic Renal Coalition (MARC), also known as ESRD Network 5, forwarded a link to the online survey to staff (e.g., facility administrators, nurses, social workers, and dietitians) at all of the dialysis facilities within its geographic region, which also includes the District of Columbia, Maryland, and West Virginia. The MARC Executive Director also forwarded the link to staff at the 17 other ESRD Networks (e.g., executive directors, quality improvement directors, and patient services directors) requesting they forward to the dialysis facilities within their respective regions. (The ESRD Network structure was established by Medicare, in 1978, approximately six years after Congress passed legislation which provided treatment for most patients diagnosed with ESRD through Medicare, regardless of age.<sup>119,120</sup> Each network exists under a federal contract with Medicare and its role is to act as a liaison between the federal government (i.e., Medicare) and the dialysis providers

within a specific geographic region of the United States. The ESRD Networks also process patient complaints against dialysis facilities and serve as a mediator.) Additionally, staff at other ESRD Networks were asked to distribute the link to facility staff within their respective regions, and professional and patient associations within the ESRD community were asked to distribute the link to their memberships.

Responses to the online scan were reviewed daily so that individuals responding with P2P experience could be contacted and interviewed to capture specific program details. Using snowball sampling technique, all individuals interviewed were asked to suggest others within the ESRD community who may have P2P experience.

In addition, representatives from the top three large dialysis organizations—DaVita, Fresenius, and DCI—were interviewed to determine if any programs exist at a corporate level.

Programs submitted through the online instrument were classified using Heisler's typology of peer support programs.<sup>15</sup>

## **Results**

### **Responses to Online Instrument**

In total, 452 responses were received, many of which were repetitive, naming the same ESRD P2P program. Of the unique responses, approximately 50 were classified as "support groups." Time did not allow for in-depth interviews with all of these individuals so a small sample was selected for key informant interviews.

In total, 31 programs were contacted to obtain additional information or schedule an interview. A total of 23 interviews were completed—11 in-depth interviews and 12 informal interviews. Informal interviews were conducted to obtain additional details and determine whether an in-depth interview was necessary because insufficient detail was submitted via the online survey. In each case, the informal interviews referenced a program(s) previously

identified. In-depth interviews were already scheduled with a different key informant or had already been completed. An additional 8 programs were contacted, but in-depth interviews were not held due to lack of response.

### **Additional Interviews**

Although not submitted via the online survey, interviews were also conducted with leaders from the three largest dialysis organizations, DaVita, Fresenius, and DCI. An interview was also conducted with Renal Network 11 because it was known that they were developing a peer mentoring toolkit. One additional in-depth interview was held with an organization that was suggested by another key informant during his interview.

### **Summary of Programs**

Four different program formats were found within the ESRD community: peer coaches; support groups (either professionally led or patient-led); telephone-based peer support; and Web- and email-based programs. None of the interviewees cited a particular theoretical foundation underpinning their unique peer program; however, program descriptions often focused on the developing patients' self-efficacy or confidence managing dialysis self-management tasks. Further, two programs had completed a formal evaluation to assess process or impact; however, only one has published its findings in the extant literature (Perry et al.). Four indicated they are collecting data to evaluate impact. Three of these were classified as peer coaching programs and one was a telephone-based program. Table 1 displays the interviews held by program type whereas Table 2 shows the specific programs identified and its format.

**Table 1: ESRD P2P Programs Interviews by Program Format**

<b>Heisler Classification of Peer Support<sup>15</sup></b>	<b>Interviews</b>
Professional-led group visits with peer exchange	0
Peer-led, face-to-face, self-management programs	0
Peer coaches	5
Community health workers	0
Support groups	4
Telephone-based peer support	2
Web- and email-based programs	2
Programs in development ( <i>unclassified</i> )	2

**Table 2: Active ESRD P2P Programs Identified**

<b>Name</b>	<b>Format</b>
The Kidney Foundation of Central Pennsylvania <sup>(a)</sup>	Peer Coaching
Mendez National Institute of Transplantation <sup>(a)</sup>	Peer Coaching
National Kidney Foundation of Florida <sup>(a)</sup>	Peer Coaching
National Kidney Foundation of Michigan <sup>(a)</sup>	Peer Coaching
Renal Empowered Mentors for Education in Nephrology & Dialysis (ReMend) <sup>(a)</sup>	Peer Coaching
Renal Support Network (RSN)	Patient-Led Support Group; Telephone-based; Web- and Email-based
National Kidney Foundation PEERS <sup>(a)</sup>	Telephone-based
Road Back to Life	Patient-Led Support Group
First Steps	Professional-Led Support Group
DaVita	Professional-Led Support Group
DaVita Pep Pals	Web- and Email-based
Home Dialyzors United <sup>(b)</sup>	Web- and Email-based; Peer Coaching
<i>Fresenius</i>	<i>Program in Development</i>
<i>Renal Network 11</i>	<i>Program in Development</i>

<sup>(a)</sup>Program has an evaluation component

<sup>(b)</sup>Interview not completed

**Peer Coaches.** Five programs using peer coaches were identified via the online survey—Renal Empowered Mentors for Education in Nephrology and Dialysis (ReMend), NKF of Michigan (NKF-MI), NKF of Florida (NKF-FL), The Kidney Foundation of Central Pennsylvania (KFCP), and Mendez National Institute of Transplantation (MNIT). No formal peer coaching programs were identified at the dialysis facility level, but rather all identified were based in non-profit patient-focused organizations. All programs paired adult mentors with adult patients on dialysis.

The goals of the programs varied in specificity, but generally focused on increasing patient engagement in their own care, and improving self-management behaviors, education, and support. The ReMend program goals aligned with Medicare’s ESRD Quality Incentive Program which links payment directly to dialysis facility performance (e.g., increase vascular access rates, decrease missed treatments, reduce fluid overload, etc.).<sup>121</sup> In addition to the goals above, NKF-FL also worked to address patient issues and complaints proactively, before they escalate to patient discharge, and often worked collaboratively with the ESRD Network responsible for Florida.

The content discussed in peer-coaching programs was not structured and did not follow a set curriculum. All interviewees stated that the interactions and topics discussed were driven by the mentor and patient, not the dialysis staff. Further, discussions were unstructured and did not follow a set curriculum. Consistent with the literature, settings ranged from the patient’s choice (e.g., home, library), to a dialysis center, to another clinical setting such as a hospital or clinic. Face-to-face visits were supplemented with phone or email exchanges. The time between encounters varied from program to program, ranging from weekly to as determined by mentor and patient. None of the programs cited a formal discharge process and the mentor-mentee

relationship tended to end organically. However, ReMend indicated that it notifies the social worker at the patient's unit once the relationship ends.

Pairing of mentors with patients varied from program to program. For example, ReMend pairs patients based on needs or similar characteristics. A patient seeking a mentor contacted the organization and provided basic background information that is then used to match the patient with a mentor based on one of a number of factors including similarity in age, ethnic background, kidney disease stage, and/or doctor. The ReMend program website has mentor bios, profiles, pictures, and Google phone numbers that patients seeking a mentor may review before requesting a specific mentor. KFCP matches patients within their specific nephrology practice as well as by gender whereas NKF-MI matches patients based on availability. Given the number of mentors at a particular facility and the demand for mentors, the program staff do not have the resources (i.e., time) to match based on patient/mentor characteristics such as race/ethnicity, age, gender, or even modality. However, if a patient wants to talk to a specific type of peer mentor within the NKF-MI, arrangements can be made to accommodate such a request.

Interviewees indicated that the majority of coaches are identified and referred by dialysis unit staff, usually the facility social worker. Some patients did seek to participate on their own and volunteered. However, it should be noted that all the programs were spearheaded by a patient or included a very active, motivated patient at the program start. Patients manage both ReMend and the NKF-FL program whereas professional staff manage the other programs interviewed.

A common goal among programs was finding the best mentors. One program required that mentors have a fistula or graft or peritoneal dialysis catheter—patients with catheters in hemodialysis were not accepted as mentors since this type of vascular access is not

recommended for long-term use because of infection risk. Other programs indicated that they were not looking for the perfect patient to be a mentor, but rather someone who has managed to live a full life and have a positive attitude despite his/her condition. Patients deemed non-adherent to self-management regimens and/or dialysis treatment schedules were not desirable to serve as coaches. MNIT found that paying mentors helped to professionalize their role and enhanced accountability.

All programs cited a formal mentor training process that included dialysis professionals, such as social workers, legal professionals, and therapists. Key topics covered included privacy, confidentiality, medical advice versus medical information, and listening skills. Education around kidney disease and the various treatment modalities was also included, since a mentor may only be familiar with his/her own modality. All programs developed a training manual or book to increase fidelity across mentors. In most cases, the initial training was complemented by additional refresher sessions, based either on a schedule or conducted on an as-needed basis by the program coordinator.

With the exception of NKF-MI (Perry et al.) and MNIT, complete formal program evaluations are lacking. When asked about evaluation, the majority of interviewees acknowledged a preference and desire for studies of program impact. Organizational capacity, knowledge, and funding were noted as significant barriers to conducting a formal program evaluation. Most were attempting to collect some data regarding impact, most notably ReMEND tracking clinical data from patient health records. All reported debriefing mentors on their experiences, but often with limited consistency or detail. Moreover, mentors' level of reporting and record keeping by mentors was limited at best. In most cases, patient mentees did not complete any evaluation.

Three of the programs—NKF-MI, NKF-FL, and KFCP—are based within a nonprofit organization. ReMend is the only program identified where peer coaching is the sole mission of the nonprofit organization. ReMend is currently supported by a large nephrology practice with some additional support from the local transplant program and Fresenius Medical Care, with a focus on promoting home dialysis and living donor transplantation. This unique position enables ReMEND greater access to clinical data for evaluation purposes.

Nevertheless, all programs mentioned that funding is necessary to maintain and/or grow the program; they are either seeking grants or trying to raise funds using other mechanisms.

The importance of working closely with the dialysis center staff, including the medical director, and the nephrology practices in the area or region was cited as the most important lesson learned. Their buy-in is critical for a number of reasons, including the referral of mentors and patients.

Another lesson cited relates to the lack of evaluation data within ESRD. Most programs recognize that evidence is required to obtain funding. ReMend has tried to incorporate evaluation right from the launch of the organization, whereas KFCP is thinking of ways to add in an evaluation component to a program that has been operating since 2008. (It should be noted that KFCP was awarded a grant from the Patient-Centered Outcomes Research Institute to conduct a RCT of their program and it is currently underway.)

**Support Groups.** Support groups were the majority of programs identified via the online environmental scan instrument. Some were currently operating while others had poor attendance and no longer were holding meetings.

Individuals from two patient-led support groups, Renal Support Network (RSN) and Road Back to Life (Puget Sound Kidney Centers), as well as two individuals from professionally



led groups, DaVita and First Steps Peer Mentor Program (Indiana University Home Dialysis), were interviewed. This sample was selected as it offered the broadest range of experience and settings. A patient started RSN as a nonprofit organization with the sole purpose of providing information and support and advocating for kidney patients through a variety of programs, including HOPELine (see “Telephone-based Peer Support” section) and KidneySpace (see “Web- and Email-based Programs” section). Also started by a patient, Road Back to Life began as a means to help patients adjust to dialysis, learn about modalities, and encourage adherence, within a small dialysis organization consisting of six units across the Puget Sound area of Washington. They also provide support to caregivers and help to train new dialysis staff by providing a patient perspective during staff training. Conversely, DaVita, a LDO, cited a corporate policy that provides facility-level social workers guidance about establishing and operating “patient mixer groups” (they do not refer to them as support groups). First Steps was started by a social worker and was designed for patients on home modalities, including home hemodialysis and peritoneal dialysis.

The topics and content discussed in the groups were not structured and did not follow a set curriculum, except for First Steps. Interviewees cited that topics are driven by patient need and/or requests. DaVita noted that it had a list of seven approved topics that could be discussed, as part of its policy, including fear of the unknown, general diet and exercise, and scheduling treatments.

All of the programs consisted of a group of patients meeting in-person to discuss issues related to treatment and coping. Program frequency and duration varied from group to group, ranging from one hour to 90 minutes, monthly, bi-monthly, or quarterly, and in a variety of places, including dialysis facilities, coffee shops, and medical offices.

Participation seems to be associated with the setting and the group leaders. For example, RSN's group is open to patients at any center within the local area. Participation seemed to vary with only a few individuals consistently attending. Conversely, Road Back to Life was only for patients in the Puget Sound Kidney Centers; the centers tended to be based in smaller communities. This thriving program has grown to include patient mentors who conduct pre-dialysis education sessions and staff training. DaVita's policy provides overall guidance to its facilities regarding implementation, but as the decision to implement a group is up to each unit so are decisions regarding patient participation and sustainability. First Steps has had some retention issues. Patients tended to come only to certain meetings or when specific topics were scheduled to be discussed. As such, the schedule has evolved from monthly to quarterly and will only focus on topics of "great interest."

Support groups vary significantly in format and reported success. Some tend to flourish while others tend to deteriorate over time, even in similar situations/settings. This difference could be related to the content or group atmosphere. For example, it is important that the group provide support to patients but not morph into complaint sessions. All interactions and discussions should be positive, empowering, and constructive.

**Telephone-based Peer Support.** Two programs were identified as telephone-based programs via the online environmental scan and as such, two key informant interviews were conducted. The programs identified were the RSN HOPELine and NKF Peers Lending Support. HOPELine refers to itself as a "poor man's patient navigator system," trying to refer and link patients (callers) to resources, including patients identified as experts in a particular topic. The Peers program goal was to pair patients with "someone who has walked in their shoes" who can provide support and empathy.

The content discussed was not structured and did not follow a set curriculum. Both programs reported that the mentor and patient drive interactions and topics discussed. RSN's HOPELine is structured more as a hotline which patients can call when they need information or support. Two patient operators staff the line from 10 am to 6 pm PST weekdays. Conversely, the NKF Peers program is structured similar to a peer coaching program, but all interactions occur via phone rather than in-person. This allows the program to operate at a national level and not be limited to a specific geographical region. A program coordinator interviews patients seeking a mentor and pairs them with a mentor based on that information. Pairing could be based on modality or topic of interest, or driven by whomever the program coordinator feels will get along well. Phone numbers remain private by scheduling calls through a third-party system (i.e., [www.ifbyphone.com](http://www.ifbyphone.com)). Frequency and time between interactions varies significantly. It could be a 1-time encounter or occur occasionally throughout the year.

Both programs use volunteers to serve as mentors. Each discussed a vetting process to ensure that the volunteers will "be a good fit." RSN and NKF both talked about having a gut sense of who will be a good mentor. Experience has shown that an individual who is not going to be a good mentor is usually identified during the training process and both programs cited a formal training process. For example, NKF conducted training through three 90-minute conference calls. Both programs talked about the use of a training manual and included an opportunity for mentors to practice using role play or mock calls. Key topics covered included privacy, a mentor's role, and medical advice versus medical information.

RSN indicated that it has anecdotal evidence of success, such as quotes and testimonials, but no formal evaluation has been conducted. Information, including demographics of callers and call topic, was collected earlier in the program but is no longer being collected. NKF is

conducting a formal program evaluation using the Hibbard's Patient Activation Measure, patient satisfaction, and behavior change. No clinical indicators are included at this time.

When the RSN program began, it was supported through a pharmaceutical grant. Operators were paid, and it helped patients "get back to work," if only in a limited or part-time capacity. Currently, the program does not have a dedicated funding stream, and operators are not compensated. As such, it has proven difficult to limit attrition or recruit additional volunteers. At the time of this interview, two patients were volunteering as mentors/phone operators. Conversely, the NKF program reports having more mentors than it can currently train and use. A single staff person oversees the program as a component of her overall position and has been unable to train all of the patients that would like to volunteer. At the time of the interview, 50 patients were active as mentors.

The success of the programs seems to be rooted in the phone-based format. It is easier to connect people because the interaction is not pre-determined by geography, and patients are not required to travel to a central location. Nevertheless, resources are necessary to operate such a program, and this continues to be a challenge for both RSN and NKF, particularly in terms of staffing.

**Web- and Email-based Programs.** Interviews were held with two individuals regarding online programs: the RSN KidneySpace and DaVita Pep Pals program. The KidneySpace goal is to allow patients to share their experiences and support one another whereas the goal of Pep Pals is to pair DaVita patients by similar hobbies or interests so that they could form a friendship and feel less isolated.

The topics discussed are not structured and do not follow a set curriculum in either program. Participants drive topic discussions. All KidneySpace interactions occur within the

moderated online discussion board; however, RSN notes that people are moving more toward social media, like Facebook. KidneySpace consists of a variety of threads that are moderated by various patient volunteers.

Pep Pals interacts predominately via letter or email exchanges, but can be by phone if both patients agree to exchange phone numbers. Patients interested in participating in the program complete an application and then are matched based on common interests and hobbies. Frequency of exchanges is left up to each dyad. Once the patients are matched, DaVita is no longer involved with the exchanges and an individual may opt out at any time.

Neither program cited tracking any specific outcomes or a formal evaluation. However, the website traffic information available for KidneySpace indicates the site has 2,716 registered members and averages 9.18 posts per day. In July 2014, there were 459,805 page views.

As indicated previously, KidneySpace is active, but RSN's Executive Director feels that the organization's Facebook page is more active. She attributes this to more individuals moving to social media platforms because it is viewed as more synchronous. Further, patients can send private messages to each other, rather than posting to a thread. Social media can allow patients to seek out others who are posting about the same issues in real time.

The program format is associated with its success; patients can participate at a level with which they are comfortable. Neither program requires a significant amount of resources; however, little is known about the accuracy of information exchanged and its impact on patients.

## **Discussion**

The format and goals of ESRD P2P programs vary across the ESRD community. Peer coaching programs appear to be popular, but this format is also resource- and time-intensive. The key benefit of this format is that it offers an ongoing relationship with a fellow patient.

Face-to-face interaction was viewed as an essential component by those implementing peer coaching programs. All key informants cited a formal training process that included training by professionals, such as social workers and legal professionals. Support groups also appear to be popular, but the success of this format was inconsistent; this was likely due to waning attendance and increased attrition over time, regardless of whether the group was led by a peer or a member of the dialysis center staff. Telephone-based as well as web- and email-based programs, operated by national organizations, were not particularly localized and reported limited success; however, they offer a significant amount of flexibility to patients. Web- and email-based and telephone programs all required a professional moderator, such as a staff person, which is often a limited resource. Barriers, regardless of program format, were patient health and transportation.

These findings are limited in that only programs that responded were interviewed. Not all programs responded to requests for interviews and their experiences may be different than those who participated. Further, time did not allow for interviewing all of those submitting information related to support groups; however, the small sample of those interviewed regarding support groups reported similar experiences.

### **Conclusion**

P2P programs vary across the ESRD community and, when used in conjunction with a comprehensive literature review, can inform the development of an ESRD P2P program.

## **Appendix B Formative Research at UVA Lynchburg Dialysis**

### **Introduction**

To assess the need for and acceptability of a P2P program among patients and staff, formative research involving semi-structured interviews, focus groups, and surveys, was conducted at UVA Lynchburg Dialysis in September 2014. These data were also used to inform the design and format of the P2P program.

### **Semi-Structured Interviews with In-Center Hemodialysis Patients**

#### **Methods**

The PI worked with facility social workers to identify both individuals who might be interested in participating in a P2P program as well as those likely not interested. Participants were then recruited by one of the facility social workers based on her perception of their ability and willingness to complete a semi-structured interview. Interview questions were designed to explore the self-management challenges patients face, and whether and how a P2P program might address these issues; the interviews also assessed patients' perceived acceptability of such a program. The interviews were audio recorded and transcribed verbatim for data analysis. Previous research has shown that many patients experience dialysis-associated cognitive decline throughout the duration of a treatment session.<sup>103,104</sup> Therefore, all patients were interviewed shortly after beginning their treatment so as to lessen the possibility of cognitive impairment. Further, all participating patients were apprised of their right to stop the interview at any time, during the informed consent process, especially if they were not feeling well. The three interviewers, a registered nurse, dialysis social worker, and health educator (the PI), were also trained to recognize signs of cognitive decline and none reported observing or detecting impairment upon debriefing.

## Results

Semi-structured interviews, ranging from 25 to 60 minutes in length, were conducted with 31 in-center patients during their in-center treatment time. Demographic information for the patient sample is provided in Table 1. The mean amount of time on dialysis total was 63.2 months (SD=65.2), while the mean amount of time at the UVA Lynchburg Dialysis facility was 57.4 months (SD=62.5). Most individuals interviewed had only received treatment at the UVA Lynchburg Dialysis facility. The mean age of the sample was 61.7 years (SD=13.6).

Patients were presented with a list of seven self-management behaviors and asked to indicate the extent to which each was perceived to be important to their care, difficult to manage, and successfully managed; each item was assessed along 4-point Likert-type scales with higher values reflecting increasing levels of importance, difficulty, and success. Of the seven tasks assessed, coming to dialysis was rated the

most important, but little variability was

found among the items (Table 2). On

average, limiting fluids and following

dietary restrictions were rated as most

difficult, and were the two tasks patients

reported having the least success

managing. This information was gleaned

through self-report, so there is likely

some response bias due to social desirability. It is unknown whether patients' clinical data corroborates this information.

When asked if talking to another patient or patients about kidney failure and how to manage it would be helpful, 77% of patients responded affirmatively. The majority (81%) also

**Table 1:  
Demographics of  
In-Center Dialysis Patients Interviewed (n=31)**

Variable	N
<b>Age</b>	
49 or less	5 (16.1%)
50-54	2 (6.4%)
55-59	7 (22.5%)
60-64	5 (16.1%)
65-69	3 (9.7%)
70-74	3 (9.7%)
75-79	3 (9.7%)
80+	3 (9.7%)
<b>Sex</b>	
Female	22 (71.0%)
Male	9 (29.0%)



reported interest in participating in a patient-to-patient program. Further, 90% agreed that a patient-to-patient program would be helpful. In terms of program format, a majority (65%) selected “in-person, one-on-one” as the preferred meeting type and 58% indicated a preference for meeting at the dialysis center on an as needed basis (29%). Finally, a majority of patients reported a desire to meet on a treatment day, either before or after treatment (33%) or during treatment” (23%), many also preferred to meet on a non-treatment day (43%),

**Table 2:  
Self-Management Tasks by Importance, Difficulty, and Level of Success**

<b>Self-Management Tasks</b>	<b>Importance<sup>1</sup></b>	<b>Difficulty<sup>2</sup></b>	<b>Success<sup>3</sup></b>
Limiting fluids	3.0 (0.8)	1.7 (1.4)	2.2 (1.1)
Following dietary restrictions	2.8 (0.9)	1.6 (1.3)	2.2 (1.0)
Taking multiple medications	3.0 (1.1)	0.9 (1.2)	2.9 (1.2)
Taking medications on a set schedule	3.0 (0.9)	0.8 (1.2)	3.2 (1.0)
Coming to dialysis the prescribed number of times per week	3.5 (0.5)	0.6 (1.2)	3.2 (0.9)
Staying for the full treatment time	3.3 (0.8)	0.4 (1.1)	3.3 (0.8)
Maintaining or getting a vascular access	3.4 (0.8)	0.5 (0.9)	3.2 (0.9)

1: Not at all important=0; somewhat important=1; moderately important=2; very important=3; extremely important=4

2: Not hard at all=0; somewhat hard=1; moderately hard=2; very hard=3; extremely hard=4

3: Not at all successful=0; somewhat successful=1; moderately successful=2; very successful=3; extremely successful=4

### **Focus Groups with Home Dialysis Patients**

#### **Methods**

The PI worked with a facility social worker and the home program nurse to identify and recruit home patients to participate in a focus group. Focus groups were used with home patients because they tend to only come to the facility about once a month, usually on the same day to see the home program nurse. It was more convenient for them to participate in a focus group rather than individual interviews. The focus groups had goals similar to the semi-structured interviews in that they sought to explore the self-management challenges dialysis patients face, and whether

and how a P2P program might address these issues; however, the willingness of home patients to mentor in-center patients as well as a peer program specific to home patients was also examined. The focus groups, moderated by the PI, were audio recorded and transcribed verbatim for data analysis. All participating patients were apprised of their right to excuse themselves at any time, during the informed consent process, especially if they were not feeling well.

## **Results**

Two focus group interviews were held with home dialysis patients. Each discussion was approximately 60 minutes in length and explored home patients' prior experience with in-center dialysis and interest in participating in a P2P program as mentors. A total of seven patients and three spouses participated in the groups. All participants received treatment in-center for a month or more prior to transitioning to a home program.

Similar themes emerged from both groups. Home dialysis patients viewed dialysis as a necessary, but small part of their lives. They were uninterested in a P2P program focusing on self-management and/or reducing hospitalization, and did not feel there was need for such a program for home patients. The theme that emerged specifically related to self-management was that home patients felt considerably better after ceasing in-center hemodialysis, and feeling healthy was considered the biggest motivation for adhering to self-management behaviors. Further, a secondary motivation was remaining at home rather than returning to a center for treatment, a possibility if a patient is not successful at self-management and home therapy. Most reported that they did not experience feelings of isolation after transitioning from in-center treatment to home therapy, citing strong support systems among family and friends. When asked about serving as mentors for in-center patients, participants did not feel they would be helpful or interested in volunteering. For example, one patient worried she would not be an effective

mentor because she would likely promote home dialysis, even though she was aware that it may not be a reasonable option for everyone.

## **Facility Staff Survey**

### **Methods**

UVA Lynchburg Dialysis employs a total of 72 individuals, on two shifts covering all three patient treatment shifts. The PI held a meeting with staff on each shift to describe the project and engage staff in a brainstorming session to identify barriers that might be encountered when implementing a P2P program; potential solutions to identified problems were also discussed. Facility staff completed a self-administered questionnaire capturing attitudes towards P2P programs and perceptions of the most significant self-management issues for patients.

### **Results**

A total of 57 surveys were received from staff members (79% response rate) and similar to the responses from in-center patients, 82.5% of facility staff agreed that a P2P program would help patients better manage their kidney disease and dialysis treatments. Further, approximately two-thirds of staff felt that such a program would make their job easier. Center staff considered limiting fluids (38.6%), following dietary restrictions (29.8%) and shortening treatments (8.8%) as the most challenging to patients. When asked what patients do well, 26.8% of staff responded that patients are most successful in obtaining or maintaining a vascular access, attending treatments (25%), and taking multiple medications (17.9%).

### **Discussion**

This formative research was conducted to determine if patients at the study site felt that a peer mentoring program would be helpful to them, and if so, how it might be structured so that it would best serve patient needs. Patients and staff at the UVA Lynchburg Dialysis supported the idea of a peer mentoring program and felt it could be useful to some patients.

In-center patients were supportive of peer mentoring and many indicated that they would participate if a program was offered at UVA Lynchburg Dialysis. Designing a program that is flexible enough to address the responses provided via the interviews will be a challenge, especially given that transportation is a significant barrier for these patients. A facility social worker estimated that approximately 70% of the patient population does not have their own transportation to treatment. They rely on friends and family, public transportation, or Medicaid transportation to attend treatment. Any intervention must address transportation. For example, when pairing participants together into dyads, patients with limited transportation must be paired with patients that have similar treatment times so that they may meet at the facility, despite many patients' desire to meet on a non-treatment day. This will limit the pairing options for the dyads.

It is surprising that the home dialysis patients were less supportive of a peer mentoring program and had little interest in participating in a program. As noted in the results, many cited a strong social network and did not feel that talking to a fellow patient would be helpful to them. A large peer support program identified during the environmental scan was for home dialysis patients (i.e., Home Dialyzors United). This patient-led organization mission is to help patients consider and access home modalities, but also provide a forum for information exchange and mentoring so that patients using home therapies do not feel isolated.<sup>122</sup> It is possible that some members of the focus group acquiesced because others voiced this opinion first, but this sentiment was consistent in both of the focus groups conducted. Further, all of the patients that participated in the focus groups had received in-center hemodialysis. It is likely that they have interesting insight to share with another in-center patient and so home patients would not be excluded from serving as mentors, if interested, despite the concern that they are not at the center

as frequently, may also have transportation issues, and may not be as committed as evidenced by the focus groups.

Staff buy-in for a peer mentoring program is essential, especially if they are going to be called on to assist and sustain the program after the study is complete. Many staff reported that they think a peer mentoring program may make their jobs easier. This is encouraging as it is thought that this will increase staff support and assistance with the program. Staff may feel that a peer program will make their jobs easier because they have a finite amount of time during a given shift to provide education and support. This may also be because they are not patients themselves and therefore it is difficult to personally relate to the many challenges of dialysis self-care; however, they did perceive the diet and fluid restriction as the most difficult for patients and this was consistent with what the patients reported in their interviews.

### **Conclusion**

A peer mentoring program is feasible for UVA Lynchburg Dialysis facility. Consideration must be given to how to bring participants together for mentor training and interactions, as transportation is a significant barrier.

## Appendix C Participant Application



## Member Application

We are excited to report *Peer Up!* begins soon and we need your help. If you are interested in participating, please answer the questions below. Your answers will be kept confidential in accordance with HIPAA laws. Please sign here to give us permission to call you in case we need to speak with you again.

**SIGN** \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Do you have a Catheter? Yes \_\_\_\_\_ No \_\_\_\_\_

4. How do you usually get to treatment? (check all that apply) I drive myself \_\_\_\_\_ Family/Friends \_\_\_\_\_  
I pay for a taxi or bus \_\_\_\_\_ Medicaid Transport \_\_\_\_\_ Medicare Transport \_\_\_\_\_ Other \_\_\_\_\_

5. When do you usually arrive for dialysis? On time \_\_\_\_\_ Early \_\_\_\_\_ Late \_\_\_\_\_

6. Would you be able to come to dialysis early to meet with your mentor/mentee?  
Yes \_\_\_\_\_ No \_\_\_\_\_ Maybe \_\_\_\_\_

7. Do you have children or grandchildren at home? Yes \_\_\_\_\_ No \_\_\_\_\_

8. Do you have pets? Yes \_\_\_\_\_ No \_\_\_\_\_

9. Who prepares your meals? (check all that apply)  
Myself \_\_\_\_\_ Family \_\_\_\_\_ Caretaker \_\_\_\_\_ Other \_\_\_\_\_

10. Do you use the Internet? Yes \_\_\_\_\_ No \_\_\_\_\_ Do you use e-mail? Yes \_\_\_\_\_ No \_\_\_\_\_

Email address: \_\_\_\_\_

11. Please list your interests, hobbies, commitments, activities, and any other information you feel will help us pair you with another patient: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
12. Usually I am very calm and relaxed in conversations.					
13. I have no fear of speaking up in conversations.					
14. Usually I am very tense and nervous in conversations.					
15. I feel very relaxed when talking to a new person.					
16. I'm afraid to speak up in conversations.					
17. I feel very nervous when talking with a new person.					

In early March, we will hold a social mixer to kick off the program. This will be approximately 1.5-2 hours in length and refreshments will be served.

18. What days and times would be most convenient for you to attend? (check all that apply)

A treatment day \_\_\_\_\_ A non-treatment day \_\_\_\_\_ A Saturday \_\_\_\_\_ A Sunday \_\_\_\_\_

Before treatment \_\_\_\_\_ After treatment \_\_\_\_\_ Other \_\_\_\_\_

19. Please tell us why you want to become a member of *Peer Up!*? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

20. Are you interested in being a: **Mentee** \_\_\_\_\_ **Mentor** \_\_\_\_\_ I'm not sure \_\_\_\_\_ (If unsure, see brochure or speak with staff)

If you are interested in being a **Mentor**, please complete the following:

Mentors must complete a brief training in February before they can participate in the program. We want to schedule the training for times that are most convenient for you and the other mentors. The training is a total of five hours in length and will include refreshments. Please tell us your preference for scheduling.

21. Place a check next to the format of the training that you think will be most convenient for you.

Option 1: Two, 2.5 hour sessions on Wednesday afternoons before treatment \_\_\_\_\_

Option 2: Two, 2.5 hour sessions Thursday afternoons before treatment \_\_\_\_\_

Option 3: One 5-hour session on a Saturday \_\_\_\_\_

Option 4: One 5-hour session on a Sunday \_\_\_\_\_

22. Would you prefer to attend: Before treatment \_\_\_\_\_ After treatment \_\_\_\_\_

On a non-treatment day \_\_\_\_\_ Other \_\_\_\_\_

## Appendix D Recruitment Flyer



Have you ever wanted to talk to someone who understands what it's like?

Do you want to help others by sharing your own personal experiences living with kidney disease?

# Coming in January 2015!

UVA Lynchburg Dialysis is trying a new program that will pair patients together to share information and support. It is the only dialysis center with this exciting program and your participation could help us make it available to dialysis patients across the country. We are only able to include a small number of people at first, so talk to your Social Worker if you are interested.



**We need a name for our program. What do you think we should call it?**

If you come up with the winning name you will win a **\$100 Walmart gift card** AND the **bragging rights** to having named this new program! Drop your ideas in the box.





We need you to make this program a success. **Apply today!**

Space is limited, so apply early before *Peer Up!* fills up!

**Where can I get more information?**

Watch the lobby bulletin board for updates and announcements.

Talk to a staff person or contact Margaret Loew-Cooney with MARC at (804) 320-0004.

A peer support program created just for you!



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This document was developed under CMS Contract #HHS-M-500-2013-NW005C. The contents of this document do not necessarily reflect CMS policy.



**peer** \ˈpɪr\ noun [C]

a person who is equal to another in abilities, qualifications, age, background, and social status

*Have you ever wanted to talk to someone who understands what it is like to be on dialysis?*

*Have you ever wanted to help others by sharing your own experience with kidney disease?*



### **What else do I need to know?**

- Members of Peer Up! will be able to use the clinic's new e-tablets and other educational resources made especially for Peer Up!
- Members will also enjoy special social events and receive program giveaways such as t-shirts or bags. Most important, participants will learn ways to care for their health, help each other, and stay out of the hospital.
- Your experience with Peer Up! can help us make the program better so that other clinics and dialysis patients across the country may try it.
- Because this is a special program, the number of people who can participate in Peer Up! is limited.

**Apply now!**

## Would I be a mentor or mentee?

### MENTORS

- Have you been on dialysis for 1 year or more at UVA Lynchburg, with at least 6 months of your treatment done in-center?
- Do you like to talk to other people and share your story?
- Do you like to help others?
- Are you willing to set aside time to meet with another person, in-person and by phone?
- Are you willing to complete surveys and other forms to help us evaluate *Peer Up!*?
- Are you willing to complete the training activities to become a mentor?

\* If you answered yes to **all** of these questions, you could be a mentor!

### MENTEES

- Are you new to dialysis, new to UVA Lynchburg, or would you just like to talk to another person who knows what dialysis is like?
- Do you like to learn new information?
- Do you think talking to another person on dialysis might help you?
- Do you sometimes find it hard to do all that you need to do to take care of yourself?
- Are you willing to set aside time to meet with another person, in-person and by phone?
- Are you willing to complete surveys and other forms to help us evaluate *Peer Up!*?

\* If you answered yes to **all** of these questions, you could be a mentee!



## What is Peer Up!?

The Mid-Atlantic Renal Coalition, the ESRD Network that covers this region, is working with UVA Lynchburg Dialysis to try a new peer mentoring program that may help hemodialysis patients support and learn from each other.

*Peer Up!* will pair people together to meet one-on-one so that they may share information and support. Pairs will consist of a mentor and mentee. A mentor is usually someone who has more experience with dialysis who can help someone with less dialysis experience learn and adjust.

### **How does Peer Up! work?**

The Peer Up! program will begin on March 1, 2015 and run through June 30, 2015. Pairs will talk at least once per week during the program. The conversations can be in-person or on the phone, but pairs should meet face-to-face at least 2 times per month. Meetings can be at the clinic or at another location that works for both people.

### **So how do I join Peer Up!?**

UVA Lynchburg is the only center with this exciting program, and we need your help! In order to be a part of the program, you must complete an application and be selected. Information from the application, like treatment schedule, hobbies, and personal preferences, will be used to pair people together.



*Do you want to  
learn ways to care  
for your health  
and stay out of  
the hospital?*

**Peer  
Up!** TOGETHER  
MAKES US  
BETTER

## Appendix F Facility Staff Patient Nomination Form



# Staff Nomination Form

### About the Program

Peer mentoring programs can help patients with end-stage renal disease (ESRD) manage their illness by informing them about disease management, providing emotional support, and teaching self-management skills. Research has shown that not only do patients who participate in peer support programs realize positive benefits, but the act of helping also benefits those who serve.

The *Peer Up!* program has been developed, implemented, and pilot-tested to help patients support one another, feel better, and even stay out of the hospital. The program could even improve our scores with the Centers for Medicare and Medicaid (CMS) Quality Incentive Program. Program participants are matched into pairs based on criteria such as treatment time, transportation options, sex, age, and interests. In each pair, one patient will serve as the mentor and the other as the mentee. Mentors participate in a fun, interactive training before serving in the mentor role and are then assigned a mentee by the staff member(s) championing the program. Topics related to self-management and support are encouraged for discussion. The intervention can run from a few months to several years; the facility determines the duration.

As staff, your input is vital to the success of the program in your facility. You know best which patients might benefit from participation in the *Peer Up!* program, either as a mentor or mentee.



### WHAT YOU SHOULD TELL YOUR PATIENTS

The *Peer Up!* program is a special project for patients with ESRD. Patients who have participated say the program is “fun” and “really helpful.” Participants will be paired together to share their experiences and knowledge. We hope that *Peer Up!* will help patients support one another, feel better, and stay out of the hospital.

### Criteria for Participation

All mentors and mentees should meet the following criteria:

- Receives in-center treatment at the facility for ESRD
- Is 18 years of age or older
- Can understand and sign informed consent
- Can comprehend English without the aid of a support person

Mentors should also meet the following criteria:

- Has been on dialysis for at least one year.
- Demonstrates a relatively positive attitude toward treatment
- Shows a willingness to share personal information about themselves either openly or on a one-to-one level
- Can follow their plan of care
- Likes to talk to people and share stories
- Likes to help others
- Will successfully complete training

Mentees should also meet the following criteria:

- Shows a willingness to receive help and support
- Could benefit from spending time with a peer mentor
- Is new to dialysis and/or the facility or is going through some health changes and would like to talk to another person who knows what dialysis is like
- Likes to learn new information
- Sometimes finds self-care difficult
- Is willing to set aside time to talk with another person, in person or by phone

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# Nomination Form

Staff member(s) leading the *Peer Up!* program in your facility would greatly appreciate help with collecting some information on the patients you nominate. Please complete one form for each nominee. If you do not know the answer to a question, you may skip it.

Your Name: \_\_\_\_\_ Nominee's name: \_\_\_\_\_

*(Your name is optional, but it will help the staff members leading the program in case they need more information about the nominated patient.)*

I have reviewed the criteria and feel this patient is a qualified candidate for:

- Mentor     Mentee

Treatment days:  MWF     TTS    Shift: \_\_\_\_\_    Bay: \_\_\_\_\_

Social worker: \_\_\_\_\_

Dietitian: \_\_\_\_\_

Access type:  AVF     AVG     Catheter     Other (please explain): \_\_\_\_\_

Mode of transportation:  Drives self     Family/Friends  
 Medical transport     Bus

This candidate's transportation is covered by Medicaid/Medicare:  Yes     No

How long has this candidate been on dialysis?

- Less than six months  
 More than six months but less than two years  
 More than two years but less than five years  
 More than five years

Thank you again for your nomination. For questions, call or email:

Jennifer St. Clair Russell (Mid-Atlantic Renal Coalition)  
[JRussell@nw5.esrd.net](mailto:JRussell@nw5.esrd.net) or (804) 320-0004.

## Appendix G Sample Agendas for Mentor Training

All mentors were required to complete training prior to meeting with their mentee. Mentors were offered two different training formats—one 5-hour training session or 2 2.5-hour training sessions. Both formats were offered multiple days and times to accommodate mentors schedules and preferences.

Below are two sample agendas reflecting these two options.

### Sample 1-Day Agenda

8:30-9:00 am	Coffee and registration
9:00-10:00 am	<b>Introduction to training and Peer Up overview</b> <ul style="list-style-type: none"><li>• Introduction</li><li>• ESRD Bingo</li><li>• What is self-care?</li></ul>
10:00-11:15 am	<b>Mentor skills and techniques</b> <ul style="list-style-type: none"><li>• Peer mentor role</li><li>• Introduction to mentoring meetings and skills</li><li>• Setting the tone and setting boundaries</li><li>• Yes, no, maybe so: Asking open questions</li></ul>
11:15-11:30 am	Break
11:30-12:30 pm	<b>Mentor skills and techniques (con't)</b> <ul style="list-style-type: none"><li>• Being a good listener</li><li>• Offering praise and encouragement</li><li>• Keeping it positive</li><li>• Building confidence and motivating others</li></ul>
12:30-1:30 pm	Lunch
1:30-2:30 pm	<b>Mentor skills and techniques (con't)</b> <ul style="list-style-type: none"><li>• Medical information vs medical advice</li><li>• Maintaining confidentiality</li></ul>
2:30-2:45 pm	Break
2:45-3:15 pm	<b>Role plays</b>
3:15-3:25 pm	<b>Responsibilities and program management</b>
3:25-3:30 pm	<b>Closing and evaluation</b>

## Sample 2-Day Agenda

### Day 1

8:30-9:00 am	Coffee and registration
9:00-10:00 am	<b>Introduction to training and <i>Peer Up!</i> overview</b> <ul style="list-style-type: none"><li>• Introduction</li><li>• ESRD Bingo</li><li>• What is self-care?</li></ul>
10:00-10:15 am	Break
10:15-11:25 am	<b>Mentor skills and techniques</b> <ul style="list-style-type: none"><li>• Peer mentor role</li><li>• Introduction to mentoring meetings and skills</li><li>• Setting the tone and setting boundaries</li><li>• Yes, no, maybe so: Asking open questions</li><li>• Being a good listener</li></ul>
11:25-11:30	<b>Closing for Day 1</b>

### Day 2

8:30-9:00 am	Coffee
9:00-9:15 am	Welcome and review of Day 1
9:15-10:30 am	<b>Mentor skills and techniques (<i>con't</i>)</b> <ul style="list-style-type: none"><li>• Offering praise and encouragement</li><li>• Keeping it positive</li><li>• Building confidence and motivating others</li><li>• Medical information vs medical advice</li><li>• Maintaining confidentiality</li></ul>
10:30-10:45 am	Break
10:45-11:15 am	<b>Role plays</b>
11:15-11:25 pm	<b>Responsibilities and program management</b>
11:25-11:30 pm	<b>Closing and evaluation</b>



Appendix H Mentor Communication Skills and Role-Play Observation Form



# Mentor Role-Play Observation Form

Mentor's Name: \_\_\_\_\_ Date of Training: \_\_\_\_\_

Training Content	Competency/Skills <i>(as demonstrated in role-playing)</i>
Professionalism/Leadership	<ul style="list-style-type: none"> <li>- Motivating others</li> <li>- Leading by example</li> <li>- Adhering to meeting times, as scheduled</li> </ul>
Relationship Building	<ul style="list-style-type: none"> <li>- Offering support</li> <li>- Establishing boundaries</li> <li>- Interacting with mutual respect</li> </ul>
Communication Techniques	<ul style="list-style-type: none"> <li>- Actively listening</li> <li>- Speaking slowly</li> <li>- Using plain language</li> <li>- Using appropriate non-verbal cues</li> </ul>
Conversation Management	<ul style="list-style-type: none"> <li>- Reframing or refocusing techniques (e.g., maintaining a positive/constructive tone)</li> <li>- Sharing personal experiences</li> </ul>
ESRD Information & Treatment Options <ul style="list-style-type: none"> <li>- Hemodialysis</li> <li>- Peritoneal dialysis</li> <li>- Transplantation</li> <li>- Medical management</li> </ul>	<ul style="list-style-type: none"> <li>- Demonstrated knowledge of content</li> <li>- Comfortable with explaining information to others</li> </ul>
Medical Advice vs. Medical Information	<ul style="list-style-type: none"> <li>- Demonstrated knowledge of content</li> <li>- Knowledge of health care professionals' roles within the facility</li> <li>- Referral process to appropriate health care professional(s) for additional information and/or answers to health questions</li> </ul>
Privacy & Confidentiality	<ul style="list-style-type: none"> <li>- Demonstrated knowledge of content</li> </ul>

<b>Mentor skills</b>	<b>Yes</b>	<b>No</b>	<b>Notes:</b>
<i>Body language</i>			
1. Leans forward			
2. Looks at mentee			
3. Nods head when mentee is speaking			
4. Uses verbal agreements to show listening			
<i>Listening skills</i>			
5. Repeats or rephrases			
6. Uses open-ended questions			
7. Asks for details			
<i>Communication skills</i>			
8. Greets and welcomes mentee			
9. Checks in about self-care			
10. Reframes to find positive			
11. Motivates and builds confidence			
12. Elicits expectation(s) from mentee			
13. Shares information and personal stories/examples ( <i>not medical advice</i> )			
14. Refers to faculty staff when necessary			
15. Keeps it professional/redirects when necessary			

## Appendix I Mentor Training Evaluation Form



### Mentor Training Evaluation

Please check which training(s) you attended:

Full Day Saturday, 2/28/15: \_\_\_\_\_

Full Day Sunday, 3/1/15: \_\_\_\_\_

Part 1 Wednesday, 2/25/15: \_\_\_\_\_

Part 1 Thursday, 2/26/15: \_\_\_\_\_

Part 2 Friday, 2/27/15, 9:00 am: \_\_\_\_\_

Part 2 Friday, 2/27/15, 12:30 pm: \_\_\_\_\_

Part 2 Other: \_\_\_\_\_

#### 1. Please provide your feedback on the Peer Up! training session.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. The trainers/facilitators were well prepared.				
2. The handouts were clear and easy to read.				
3. The information was useful.				
4. The instructions for activities were clear.				
5. The role plays allowed me to practice new skills.				
6. There was enough time to practice new skills.				
7. All my questions were answered.				
8. The training was well-organized.				
9. The training was scheduled at a convenient time.				
10. The training kept my interest.				
11. The amount of information covered during the training was appropriate.				

2. Please tell us if you feel ready to use your mentoring skills.

	<b>Totally confident</b>	<b>Somewhat confident</b>	<b>Not very confident</b>	<b>Not at all confident</b>
1. I can share tips and experience about living with kidney disease.				
2. I can name three characteristics of a good mentor.				
3. I am able to use my body to show someone I am listening.				
4. I am able to respond to someone to show them I heard what they said.				
5. I can ask an open-ended question.				
6. I can define “stages of change”.				
7. I can use praise and encouragement during a conversation.				
8. I can lead a Peer Up! meeting/session.				
9. I can keep information private.				
10. I can set a professional boundary with my mentee.				
11. I can ask for help from Peer Up! staff or other mentors.				
12. I can keep a conversation on a positive tone.				

**For each of the following questions, please give as much information as possible.**

1. What would you say was the **most helpful** topic covered in the Peer Up! mentor training? \_\_\_\_\_

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2. What would you say was the **least helpful** topic discussed during the Peer Up! mentor training?

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3. What additional training topics should have been covered? \_\_\_\_\_

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4. Which tools, materials and/or resources offered do you plan to use as a mentor? \_\_\_\_\_

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5. How can we improve the Peer Up! mentor training? \_\_\_\_\_

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## Appendix J Participant Confidentiality Form



## Confidentiality Agreement

Confidentiality and privacy are important for both mentors and mentees. Mentors and mentees should keep the personal information shared during peer time private and not share it with other patients, friends, family, or dialysis staff.

All forms, logs, and notes should be kept confidential and private. Please do not leave any forms or paperwork unattended. All forms and logs should be submitted right after they are completed. All forms and logs should be given to either a *Peer Up!* staff person or put in one of the *Peer Up!* boxes.

A private *Peer Up!* area will be set up in the waiting area for you to use any time you meet at the facility. If the area is in use, either wait until it is available or check with the receptionist to see if another private area, like the patient consultation room, is available.

Please keep in mind that there are times when personal and private information should be shared, for example if someone may harm himself or herself or others. In that case, you must immediately notify a charge nurse or facility social worker.

Any mentor or mentee violating confidentiality in a non-emergency situation may be asked to leave the *Peer Up!* program.

**I have read the above information and agree to adhere to the *Peer Up!* confidentiality policy.**

\_\_\_\_\_ Yes                      \_\_\_\_\_ No

**Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## Appendix K Meeting Log



# Mentor/Mentee Contact Log

Please complete this form each time you have contact with your mentee.

---

Mentor Name: \_\_\_\_\_

Mentee Name: \_\_\_\_\_

Date: \_\_\_\_\_

How long did this contact last? \_\_\_\_\_

---

### How did you and your mentee meet?

- In the *Peer Up!* Lounge
- In the Clinic lobby
- In the Treatment Area
- Dining Out
- By Telephone
- By Email
- By Text

### What did you and your mentee talk about?

- Fluid Control
- Dietary Restrictions
- Medications
- Vascular Access
- Hospitalization
- Attending treatments as scheduled
- Staying for full treatments
- General Dialysis Information

Other \_\_\_\_\_

**What materials did you use?**

- Information in the *Peer Up!* Lounge
- The e-Tablet
- Other information from the facility
- None

**Did you suggest your mentee talk with anyone?**  **Yes**  **No**

- If yes, who?*
- Charge Nurse
  - Dietitian
  - Nurse/Technician
  - Social Worker
  - Nephrologist

Other \_\_\_\_\_

**Did you talk to anyone about your Peer time?**  **Yes**  **No**

- If yes, who?*
- Charge Nurse
  - Dietitian
  - Nurse/Technician
  - Social Worker
  - Nephrologist

**When will you and your mentee meet again?** \_\_\_\_\_



## Appendix L Participant Consent



## Member Consent for Participation and Use of Information

Name \_\_\_\_\_

This form explains the *Peer Up!* program and provides answers to your questions about what you will be doing if you choose to participate. If you have more questions after reading this form, please feel free to contact Jennifer St. Clair Russell with MARC at (804) 320-0004 or reach out to your charge nurse or clinic social worker.

### What is *Peer Up!*?

UVA Lynchburg Dialysis and the Mid-Atlantic Renal Coalition have paired to offer this exclusive program. *Peer Up!* will pair patients (peers) for four months to learn how a peer mentoring/ support program of 25 pairs of patient peers can increase their self-management skills and reduce hospitalizations among in-center hemodialysis patients. One mentor and one mentee make up a pair of “peers.” If you would like to participate, you will need to sign this form, so please read it carefully. A signed copy of this form will be available to take home.

### Why am I being asked to participate?

You are being asked to participate because you either

- completed an application,
- were nominated by a staff person, or
- told someone you wanted to participate.

We would like to have a minimum of 25 pairs of peers so that we can learn as much as possible about how mentoring can help dialysis patients with their self-management skills. Self-management skills are those actions that patients are encouraged to take by medical staff and are considered the best ways to manage ESRD while on dialysis. Limiting fluids and following a special diet are two examples of such actions.

## **How do I get into the program?**

Patients interested in the program should complete an application and give it to a charge nurse. The application has questions that will help us determine if a patient is eligible to be a mentor or mentee.

## **Eligibility requirements include:**

### **Mentors**

- Mentors should have a minimum of one year's experience on dialysis.
- Mentors will be patients who have been at UVA Lynchburg for at least the past six months.
- Mentors will agree to complete paper/pencil surveys and other forms to help evaluate the program.
- Mentors will agree to complete a 5-hour training in March.
- Mentors will agree to complete a 1.5-hour training booster that will be offered in late April.
- Mentors will agree to set aside time to meet with a mentee, in-person by telephone, or by email.

### **Mentees**

- Mentees will agree to complete paper/pencil surveys to help evaluate the program.
- Mentees will agree to set aside time to meet with a mentor, in-person by telephone, or by email.
- Mentees should be interested in learning new information.
- Mentees will be willing to talk with a mentor about kidney disease and ways to manage it.

Patients with a current diagnosis of mental illness, including major depression, dementia, Alzheimer's disease, schizophrenia, bipolar disorder, alcoholism, or drug abuse, will be ineligible to participate. Individuals who cannot read or write will also not be eligible.

## **What will I be asked to do?**

During the 4-month program members will be asked to

- Attend two social mixers
- Meet with their peer weekly, in-person or by phone or email
- Complete three paper/pencil surveys

Mentors will also be asked to participate in a 5-hour training in February and a 1.5-hour booster training in late April, and complete contact logs to keep track of peer time.

### **What kinds of questions will be on the surveys?**

The short paper/pencil survey questions are about

- Vascular access
- Confidence level in taking care of themselves
- Social support
- Knowledge of dialysis
- Behaviors used to manage ESRD

The information collected from these surveys is protected according to HIPAA laws. After collecting all the information, the research staff will be able to review it to evaluate the program.

### **How much of my time and money will this require?**

The amount of time you spend participating in the program will vary based on your role as mentor or mentee and on your level of involvement and interest. Peers will not get any money to be in the program and will have to arrange for their own transportation to meet. Peers will enjoy snacks during the two social mixers and during the mentor trainings (depending on their length). Members will also receive a number of giveaways created to promote the program, including bags, t-shirts, and water bottles.

### **What are the risks of being in this study?**

There is little risk to participants in this study. A possible risk may be discomfort when answering questions related to kidney failure and self-care behaviors. Staff will refer participants who become distressed while completing a paper/pencil survey to the social worker.

### **Could being in this study help me?**

Participants may not receive any direct benefit, however some participants may feel good about themselves because they are sharing with a peer and/or contributing to research. This research may tell us if a peer mentoring program could help other dialysis patients. It could also lead to clinics starting their own *Peer Up!* program or to informing additional research.

**What are my rights?**

1. **You have the right to say no and not participate or give your consent.** Your participation, or decision not to participate, in this program does not affect your treatment or your Medicare benefits in any way.
2. **You have the right to change your mind.** You can give your consent now and change your mind later. You can stop at any time.
3. **You have the right to privacy.** Your personal information will be kept private and not shared with anyone. Only MARC and UVA Lynchburg will have access to your personal information.
4. **You have the right to confidentiality.** Staff will follow HIPAA rules to protect confidentiality and privacy. Mentors and mentees are asked to keep all personal information discussed and shared confidential.

**Before signing**

Before you sign this form, please ask questions about any part of this study that is not clear to you. If staff has answered all your questions and you wish to participate, sign below. If you sign this form, it means that you agree to join the study, and you give researchers permission to access your medical record. You will receive a copy of this signed consent.

**Consent From Adult**

_____	_____	_____
PARTICIPANT (SIGNATURE)	PARTICIPANT (PRINT)	DATE

To be completed by participant if 18 years of age or older.

**Person Obtaining Consent**

By signing below, you confirm that you have fully explained this study to the potential subject, allowed them time to read the consent or have the consent read to them, and answered all their questions.

_____	_____	_____
PERSON OBTAINING CONSENT (SIGNATURE)	PERSON OBTAINING CONSENT (PRINT)	DATE

Appendix M University of Virginia IRB Determination



17913

DETERMINATION OF HUMAN SUBJECTS RESEARCH FORM

Date of Submission	<u>01-05-15</u>
PI Name - ONE name only	<u>Deborah Cote</u>
Contact Name:	<u>none</u>
Email:	<u>dcote@virginia.edu</u>
Phone:	<u>(434)924-8293</u>
UVa Messenger Mail Box #	<u>na - Lybchburg Dialysis Clinic</u>
Project/Protocol Title:	<u>Evaluation of a Peer-to-Peer Intervention to Increase Self-Management among Adult In-center Hemodialysis Patients</u>

**FOR IRB-HSR OFFICE USE ONLY**

Project is determined to **NOT** meet the criteria of Research with Human Subjects and therefore is not subject to IRB-HSR Review.  
 NOTE: If you will collect health information along with any HIPAA identifier (see Appendix A), you are required to follow UVa policies to protect the data. See Appendix B: Privacy Plan.  
 IRB-HSR # 17913

Project is determined to be Human Subjects Research and must be submitted to the IRB-HSR for review and approval prior to implementation

[Signature]  
 Signature: IRB-HSR Chair, Vice Chair or Director

01-20-15  
 Date

## Appendix N Virginia Commonwealth University IRB Determination



Jennifer St Clair Russell <stclairrussj@mymail.vcu.edu>

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### Notification: IRB HM20003775 Thomson - IRB Correspondence

---

IRBPANELB@vcu.edu <IRBPANELB@vcu.edu>  
Reply-To: IRBPANELB@vcu.edu  
To: stclairrussj@vcu.edu

Mon, Aug 10, 2015 at 2:46 PM



Office of Research  
Office of Research Subjects Protection  
BioTechnology Research Park  
800 East Leigh Street, Suite 3000  
P.O. Box 980568  
Richmond, Virginia 23298-0568

(804) 828-0868  
Fax: (804) 827-1448

TO: Maria Thomson  
CC: Jennifer St Clair Russell  
FROM: VCU IRB Panel B  
RE: Maria Thomson ; [HM20003775](#) Evaluation of a Patient Peer Mentoring Program to Increase Self-Management in Hemodialysis

Section 45 CFR 46.102(d) of the HHS Regulations for the Protection of Human Subjects defines **research** as "a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. Activities which meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program which is considered research for other purposes."

Section 45 CFR 46.102(f) of the HHS Regulations for the Protection of Human Subjects defines a **human subject** as "a living individual about whom an investigator conducting research obtains:

1. Data through intervention or interaction with the individual, or
2. Identifiable private information"

To be subject to the regulations, a study must meet the definitions for BOTH "human subject" AND "research". While your study may fit one of these definitions, it does not fit both. Therefore, your study is not subject to the regulations and no IRB review or approval is required before you proceed with your research.

Thank you for informing us of the project. If we can be of service with respect to future research studies, please contact us.

If you have any questions, please contact the Office of Research Subjects Protection (ORSP) or the IRB member(s) assigned to this review. Reviewer contact information is available by clicking on the Reviewer's name at the top of the study workspace.

Thank you for your continued collaboration in maintaining VCU's commitment to protecting human participants in research.

## Appendix O Participant Satisfaction (Mentor)

### Peer Up! Evaluation Sheet

1. Overall, how would you rate your experience with your mentee?
- Excellent
  - Very Good
  - Good
  - Fair
  - Poor



Please mark the box that matches your level of agreement with each of the following statements.

Mentors		Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
2.	The talks I had with my mentee were helpful to me.	5	4	3	2	1
3.	Working with my mentee helped me feel better.	5	4	3	2	1
4.	Sharing my story was helpful to me.	5	4	3	2	1
5.	Meeting with my mentee made it easier for me to cope with my kidney disease.	5	4	3	2	1
6.	I learned new information from my mentee.	5	4	3	2	1
7.	Serving as a role model to my mentee made me take better care of myself.	5	4	3	2	1
8.	I helped my mentee learn to take better care of himself or herself.	5	4	3	2	1
9.	The mentor training sessions prepared me to be a mentor.	5	4	3	2	1
10.	I have used what I learned in the mentor training sessions to take care of myself.	5	4	3	2	1

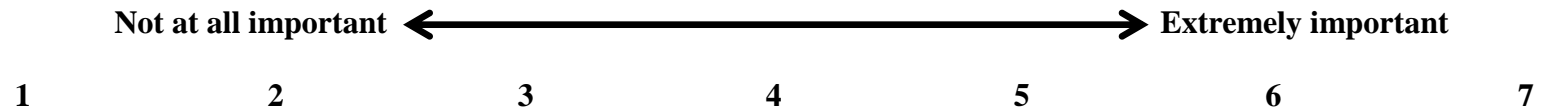
11. Participating in the *Peer Up!* program encouraged me to think about other treatments for kidney failure.
- Yes
  - No
12. If yes, what other treatments have you thought about?
- Transplant
  - Home hemodialysis
  - Peritoneal dialysis
  - Other \_\_\_\_\_
13. What did you like most about meeting with your mentee?
14. What did you like least about meeting with your mentee?
15. Please list at least one thing you learned **from your mentee** that you have used to care for yourself.



16. How likely is it that you will continue to meet with your mentee?

- Extremely likely
- Likely
- Neither unlikely or likely
- Unlikely
- Extremely unlikely

17. On a scale of 1 to 7, with 1 being not at all important and 7 being extremely important, how important is it to you that UVA Lynchburg Dialysis offer a peer program?



18. What other suggestions or thoughts do you have regarding your experience?

## Appendix P Participant Satisfaction (Mentee)

### Peer Up! Evaluation Sheet

1. Overall, how would you rate your experience with your mentor?

- Excellent
- Very Good
- Good
- Fair
- Poor



Please mark the box that matches your level of agreement with each of the following statements.

Mentees		Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
2.	The talks I had with my mentor were helpful to me.	5	4	3	2	1
3.	Talking more with my mentor would have been helpful to me.	5	4	3	2	1
4.	My mentor sharing his or her story was helpful to me.	5	4	3	2	1
5.	Meeting with my mentor made it easier to cope with my kidney disease.	5	4	3	2	1
6.	I learned new information from my mentor.	5	4	3	2	1
7.	I felt comfortable talking to my mentor.	5	4	3	2	1
8.	I felt comfortable asking my mentor questions.	5	4	3	2	1
9.	I felt better after talking with my mentor.	5	4	3	2	1
10.	My mentor listened carefully to me.	5	4	3	2	1
11.	My mentor was available to me.	5	4	3	2	1
12.	I would recommend other dialysis patients talk with a mentor like mine.	5	4	3	2	1
13.	Meeting with my mentor has helped me take better care of myself.	5	4	3	2	1

14. Talking with my mentor encouraged me to think about other treatments for kidney failure.  
 Yes  
 No
15. If yes, what other treatments have you thought about?  
 Transplant  
 Home hemodialysis  
 Peritoneal dialysis  
 Other \_\_\_\_\_
16. What did you like most about meeting with your mentor?
17. What did you like least about meeting with your mentor?
18. Please list at least one thing you learned from your mentor that you have used to care of yourself.

19. How likely is it that you will continue to meet with your mentor?

- Extremely likely
- Likely
- Neither unlikely or likely
- Unlikely
- Extremely unlikely

20. On a scale of 1 to 7, with 1 being not at all important and 7 being extremely important, how important is it to you that UVA Lynchburg Dialysis continue the *Peer Up!* program?



21. What other suggestions or thoughts do you have regarding your experience?

## Appendix Q Participant Survey

Thank you for participating in the *Peer Up!* program and for completing this survey.

Please answer all of the questions in this survey as best you can. If at any time you have a question, need to take a break, or want to finish it at another time, please see a *Peer Up!* staff person.

We estimate that this survey should take about 20 minutes. All of your responses will be kept confidential. We will not share any of your responses with the facility staff. Your responses will not affect your Medicare benefits in any way.

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These first few questions are about your experience with dialysis and the type of vascular access you have.

1. What treatments have you used for kidney failure? Please check all that apply.

- In-center hemodialysis
- Nocturnal in-center hemodialysis
- Nocturnal home hemodialysis
- Short daily home hemodialysis
- Continuous ambulatory peritoneal dialysis (CAPD)
- Continuous cycling peritoneal dialysis (CCPD)
- Other (Please specify: \_\_\_\_\_)

2. What month and year did you start in-center hemodialysis? \_\_\_\_\_ / \_\_\_\_\_  
(month)/(year)

2a. (If applicable) What month and year did you re-start in-center hemodialysis?  
\_\_\_\_\_ / \_\_\_\_\_  
(month)/(year)

3. What type of vascular access do you have?

- AVF (*Skip to #4*)
- AVG (*Skip to #4*)
- Catheter (*Please go to #3a*)
- Not Sure (*Skip to #4*)

3a. Thinking about the vascular access you use for dialysis, would you say that you...

- Are not ready to schedule an appointment with a doctor about placing an AV fistula or graft in the next 3 months
- Are thinking of scheduling an appointment with a doctor about placing an AV fistula or graft in the next 3 months
- Are planning to schedule an appointment with a doctor about placing an AV fistula or graft in the next month
- Have already scheduled an appointment with a doctor about placing an AV fistula or graft
- Have attended an appointment with a doctor about placing an AV fistula or graft
- Have an AVF placed but it is not useable at this time
- Don't know

**Now we would like to get an idea of the different things you do to take care of yourself. How often have you done each of the following in the past 4 weeks?**

**Please check the box that matches how often you have done each activity. Mark only one answer for each item, a – g.**

4. How often have you done each of the following in the past 4 weeks?	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. Limited your fluids?					
b. Followed the diet prescribed by your doctor or dietitian?					
c. Taken all of your medicines?					
d. Taken medicines on a set schedule?					
e. Came to dialysis your prescribed number of times per week?					
f. Stayed for your full treatment time?					

**Next, we would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.**

5a. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

<b>Not at all confident</b>	1	2	3	4	5	6	7	8	9	10	<b>Totally confident</b>
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5b. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

<b>Not at all confident</b>	1	2	3	4	5	6	7	8	9	10	<b>Totally confident</b>
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5c. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

<b>Not at all confident</b>	1	2	3	4	5	6	7	8	9	10	<b>Totally confident</b>
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5d. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

<b>Not at all confident</b>	1	2	3	4	5	6	7	8	9	10	<b>Totally confident</b>
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5e. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

<b>Not at all confident</b>	1	2	3	4	5	6	7	8	9	10	<b>Totally confident</b>
-----------------------------	---	---	---	---	---	---	---	---	---	----	--------------------------

5f. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

<b>Not at all confident</b>	1	2	3	4	5	6	7	8	9	10	<b>Totally confident</b>
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**These questions will check what you know about your health as a dialysis patient. For each question, mark an “X” in the box next to the one best answer.**

6a. Dialysis patients are more likely to get infections. To prevent flu, pneumonia, and Hepatitis B infections, you need to:

- Take antibiotics often
- Get vaccinated
- Avoid strenuous activity
- Avoid traveling

6b. Your doctor tells you that your hematocrit is 25%. This may cause you to feel:

- Pain in your bones
- Ringing in your ears
- Tired and worn out
- Kidney pain

6c. You are ordering food from a restaurant menu. Which item below is best for you to avoid to control your potassium?

- Steamed rice
- Corn
- Baked potato
- Noodles

6d. The preferred dialysis access that has the least chance of problems is a:

- Fistula
- Graft
- Tubule
- Catheter

6e. The best way to prevent the spread of germs is to:

- Use antibiotics
- Stay away from crowds
- Spray countertops
- Wash hands

- 6f. A phosphorus binder is a drug that protects your heart and bones. You should take it:
- With food
  - 1 hour before meals
  - 1 hour after meals
  - At bedtime
- 6g. A type of dialysis that can be done at home or work, usually without a machine, is called:
- CAPD (Continuous Ambulatory Peritoneal Dialysis)
  - CCPD (Continuous Cycling Peritoneal Dialysis)
  - HD (Hemodialysis)
  - HHD (Home Hemodialysis)
- 6h. If you want a kidney transplant, the best chance for success of the transplant is to get a kidney from a well-matched:
- Relative
  - Friend
  - Person born with an extra kidney
  - Person who just died (cadaver)
- 6i. You are on dialysis, and a fire occurs. To get off dialysis quickly, a helper or you should:
- Clamp and cut
  - Sit and open saline
  - Rinse and pull needles
  - Stand and take blood pressure
- 6j. After asking your doctor, you start an exercise routine. You know that most dialysis patients:
- Cannot increase their activity
  - Are limited to low energy activities
  - Cannot do stretching exercises
  - Are able to exercise during dialysis

- 6k. If you drink too much fluid, you are most likely to have:
- Double vision when reading
  - Nausea and vomiting after eating
  - Severe headaches when out in the sun
  - Trouble breathing when you lie down
- 6l. When you buy “over-the-counter” items at the drug store for constipation, a good choice is:
- Mylanta
  - Metamucil
  - Alka Seltzer
  - Fleet’s Enemas
- 6m. You are feeling depressed, and you are having difficulty adjusting to your life on dialysis. You can talk with anyone, but the person most trained to help you with this is the:
- Social worker
  - Dietitian
  - Nurse
  - Senior technician
- 6n. Your boss is concerned because you are missing some work to have dialysis treatments. You know that dialysis patients:
- Cannot work full-time
  - Can sometimes miss dialysis treatments for work
  - Do best when they work from home
  - Are protected by the Americans with Disabilities Act
- 6o. If the dietitian tells you that your albumin is low, you need to eat more:
- Fiber
  - Protein
  - Fats
  - Vitamins

6p. Before dialysis treatments, the technician tells you that you have gained too much weight since the last treatment. The best thing for you to do is:

- Reduce your calorie intake
- Increase the amount of exercise you get
- Reduce the amount of fluid you drink
- Increase your dialysis blood flow rate.

6q. The best sign that your fistula or graft is clotted is if:

- You have severe pain in the arm
- You see an open sore on the skin near the access
- You can't feel the access pulse or thrill
- You feel a lump near the access

6r. The ESRD Network office is a place where you can go for:

- Making a complaint about your dialysis clinic
- Buying medicines
- Getting dialysis supplies
- Dialysis while traveling

6s. The most important member of your health care team is:

- The doctor
- You
- Your family
- The nurse

6t. The doctor tells you that your URR is low. This can be improved by:

- Starting an exercise routine
- Increasing your protein intake
- Increasing your dialysis treatment time
- Increasing your dose of EPO (Epogen)

6u. Dialysis patients are asked not to take:

- EPO
- St. John's Wort
- Protein supplements
- Tylenol

6v. The dietitian has told you to limit how much salt you eat. When shopping for groceries, the item on the food label that tells you how much salt is in the food is:

- Fiber
- Cholesterol
- Saturated fat
- Sodium

6w. If you sometimes skip a dialysis treatment, you know that this can:

- Shorten your life span
- Provide a good break for your access
- Help you recover better if you are sick that day
- Boost your spirits if you are depressed

**People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle the number on each line.**

7. If you needed it, how often is someone available...	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
a. You can count on to listen to you when you need talk?					
b. To give you information to help you understand a situation?					
c. To give you good advice about a crisis?					
d. To confide in or talk to about yourself or your problems?					
e. Whose advice you really want?					
f. To share your most private worries or fears with?					
g. To turn to for suggestions about how to deal with a personal problem?					
h. Who understands your problems?					

8. How often do you...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Talk with other patients about your overall health?					
b. Talk with other patients about how to manage your kidney disease?					
c. Talk with other patients about dialysis and its effects on your life?					
d. Talk with other patients about feelings, such as helplessness or frustration?					

**You are almost finished! These last few questions are about you. Please pick the answer that fits you best.**

9. In general, would you say that your health is...

- Excellent
- Very good
- Good
- Fair
- Poor

10. How old are you? \_\_\_\_\_

11. What is your sex?

- Female
- Male

12. What is your marital status?

- Single/never married
- Married/cohabitating
- Divorced
- Separated
- Widowed

13. Are you of Hispanic or Latino(a) origin or descent, such as Mexican, Puerto Rican, Cuban, or other Spanish background?

- Yes (*Please go to #13a*)
- No (*Skip to #14*)

13a. Are you Mexican, Cuban, Puerto Rican, or some other nationality?

- Mexican
- Cuban
- Puerto Rican
- Other (with which nationality do you identify: \_\_\_\_\_)

14. What is your race?

- African American (*Skip to #15*)
- Asian/Pacific Islander (*Please go to #14a*)
- Caucasian (*Skip to #15*)
- American Indian/Alaskan (*Skip to #15*)
- Mixed race (with which races do you identify: \_\_\_\_\_)  
(*Skip to #15*)
- Other (with which races do you identify: \_\_\_\_\_)  
(*Skip to #15*)



14a. Would that be Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or some other Asian?

- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other (Specify:\_\_\_\_\_)

15. Are you currently employed?

- Yes (*Please go to #15a*)
- No (*Skip to #16*)
- Don't know (*Skip to #16*)

15a. Is your position full-time or part-time?

- Full-time
- Part-time
- Don't know

16. What is the highest grade or degree you have completed? \_\_\_\_\_ (Grade/Degree)

- Less than high school (<12)
- High school graduate/ GED (12)
- Some college, no degree (11)
- Associate's degree, cosmetology school, LPN (14)
- More than associate's degree, but no bachelor's degree (15)
- Bachelor's degree (16)
- Some graduate school, no degree (17)
- Master's degree (18)
- Uncompleted graduate training beyond a master's degree, ABD (all but dissertation) (19)
- Doctorate (20)

17. What is your annual household income?

- \$0 – 19,999
- \$20,000 – 39,999
- \$40,000 – 59,999
- \$60,000 – 79,999
- \$80,000 – 99,999
- \$100,000 or more
- Don't know

***Thank you for your time!!***

## Vita

Jennifer St. Clair Russell was born on December 11, 1973 in Oregon, Ohio and is an American citizen. She graduated from Oak Harbor High School, Oak Harbor, Ohio in 1992. She graduated with honor from the University of Toledo, Toledo, Ohio in 1996 with a Bachelor of Education–Community Health. She received a Master of Science in Education –Public Health in 1997 from the University of Toledo as well. She also earned a graduate-level certificate in Web-based Instructional Design from George Washington University, Washington, DC, in 2001 and is recognized as a Master Certified Health Education Specialist by the National Commission on Health Education Credentialing.

She will graduate with her Doctor of Philosophy degree in Social and Behavioral Sciences from Virginia Commonwealth University in Richmond, Virginia in August 2016.

### **Professional Research Positions**

2016–present, Director, Coalition for Supportive Care of Kidney Patients, WVMI/Quality Insights (d/b/a Mid-Atlantic Renal Coalition), Richmond, VA

Ms. St. Clair Russell was awarded a research grant (R03) by AHRQ in September 2015 to explore the barriers that prevent nephrologists and nephrology fellows from holding palliative care discussions with patients diagnosed with kidney failure. This research seeks to identify facilitators to such conversations, with the intention that training programs can be based on these findings and equip nephrologists and fellows with the necessary skills to have palliative care discussions in a timely manner.

She also serves as a co-principle investigator on a grant funded by The Patrick and Catherine Weldon Donaghue Medical Research Foundation focusing on shared decision-making and advance care planning among patients with advanced chronic kidney disease

2014–2016, Principal Investigator and Director of CMS Special Innovation Projection, WVMI/Quality Insights (d/b/a Mid-Atlantic Renal Coalition), Richmond, VA

2012–2014, Graduate Research Assistant, Department of Social & Behavioral Health, Virginia Commonwealth University, Richmond, VA