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**PEER MENTORING FOR PATIENTS WITH CHRONIC KIDNEY DISEASE AND THEIR
CAREGIVERS:**

A QUALITATIVE STUDY

A Thesis in

Public Health Sciences

by

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ABSTRACT

Background: Peer mentorship may enhance patient engagement for those with advanced chronic kidney disease (CKD) (stages 4 and 5); yet, the approaches and qualities (i.e., online vs in-person) that make a good mentor are unclear. This study sought to determine these qualities by conducting focus groups with mentees from the mentorship program in a randomized peer-education study.

Methods: 11 focus group meetings were conducted with mentees (n=34). Mentees were patients with advanced CKD and their caregivers who were matched with trained patient and caregiver peer-mentors for in-person or online mentorships. Meetings were audio-recorded, transcribed, and thematically analyzed by three facilitators who concurred with the significant results.

Results: Three important themes emerged: (1) Compared with phone or online communication, in-person meetings facilitated meaningful partnerships; (2) good mentors were relatable and good listeners; and (3) mentorship program provided support.

Conclusions: A mentorship program for patients with advanced CKD may provide them with substantial support, particularly when mentorship is conducted in-person and the mentor is a relatable, empathetic listener.

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Chapter 1 Introduction

1.1 The Impact of Chronic Kidney Disease

Numerous studies about End Stage Renal Disease (ESRD) or Chronic Kidney Disease (CKD) patients conclude that patients on dialysis, particularly on hemodialysis, have lower scores in more sections of quality of life compared to transplanted patients.¹⁻⁶ Generally, peritoneal dialysis tends to provide a higher quality of life and is recommended over hemodialysis.^{3,7-9} Although treatment options can produce a higher quality of life, not all patients receive such a realistic opportunity and are limited in their renal-replacement therapy options. Some patients must change treatments for the less optimal at times.^{2,10}

With CKD patients weighed down by a lower quality of life and a finite number of renal replacement therapy options, it is important to create the feeling of tangible options in patients and ensure activity in their healthcare. The stress and required activity of patients to maintain their healthcare can result in a burden in caregivers.^{11,12} Therefore, a possibility to decrease the burden that caregivers face is to increase patient engagement in their healthcare. There have been a number of studies on the benefits of patient engagement, activation, and self-management in their own healthcare with some calling for the implementation of programs or additional interventions.¹³⁻¹⁶ While studies that have incorporated supportive, educational, or mentorship programs for patients were instrumental for the renal population, many of the studies called for interventions that are more organized to further benefit patients.^{14,17-25}

1.2 Study Objectives

We matched patients with CKD stage 4 and stage 5 and their caregivers with trained mentors for support with one-on-one communication. The goals of the peer-mentorship intervention were to improve patient engagement, kidney disease quality of life, and caregiver burden. The objective of this current qualitative study was to understand the qualities that make a

good mentor based on the results of 11 focus group meetings conducted in the central PA area after mentees communicated online or face-to-face with their mentors.

Chapter 2 Methods

2.1 Study Participants: Recruitment and Design

Participants were primarily referred by renal social workers and other care providers to the Kidney Foundation of Central PA's (KFCP) Patient and Family Partner Program (PFPP). Mentors, patients and their caregivers, completed the PFPP's eight week training. There were three eight week mentor trainings and two "refresher" mentor trainings. The refresher classes were offered for individuals that previously completed the mentor trainings. The mentors that participated in the refresher classes wanted to review the major points of the full eight week trainings. The mentor-mentee matches were patient to patient and caregiver to caregiver. Additionally, the mentors and mentees were matched as close as possible in age, gender, and modality. Modality was defined for our study as the participants' type of treatment. For example, the program would attempt to match a mentor on hemodialysis with a mentee on hemodialysis.

The patients and caregivers enrolled in the PFPP that were interested in the study were screened for eligibility. Enrolled participants included patients diagnosed with CKD stage 4 or stage 5 and caregivers of such patients. All study participants were over the age of 18, and they were able to read and write in English at an eighth grade level. Mentees were randomized into one of three interventions: face-to-face interaction with a mentor, online interaction with a mentor, or no interaction with a mentor (control). After screening and enrollment, the mentees completed baseline assessments. The assessments comprised of the KDQOL-36 to measure kidney disease quality of life, PAM-13 to measure patient activation, and Zarit Burden Interview to measure caregiver burden. Demographic variables such as age, gender, and race were collected at the baseline. Although mentors were not asked to complete assessments, they were asked to participate in the focus group meetings. The mentor and mentee focus group meetings were held separately.

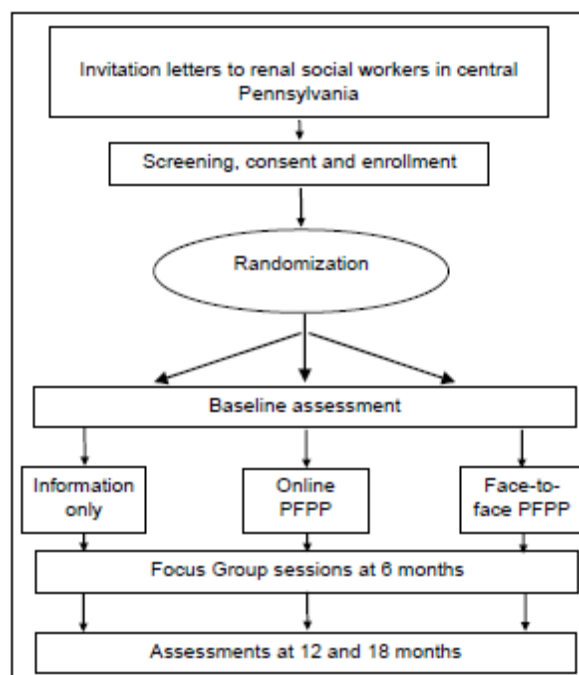


Figure 2-1. Enrollment, Randomization, and Assessment Timeline

The mentees communicated with their mentors online or face-to-face for at least one month before attending a focus group meeting. The face-to-face intervention involved mentors and mentees communicating once a week over the phone and meeting at a convenient location once a month in-person. The online intervention involved communication using the website MyKidneyCoach. There were no interactions in-person or over the phone between the mentors and the mentees in the online intervention. Since mentees were randomized into only one of the interventions, mentors were asked to communicate with a couple mentees online and face-to-face if possible. Mentees in the control group were not invited to the focus groups because they did not receive the mentorship intervention.

The three facilitators roughly asked 10 questions from the focus group guide (Textbox 1), which revolved around the participants' partnership experiences and their thoughts on what could be improved to benefit partnerships. Since recruitment for our study required at least one year for completion, several focus group meetings were necessary to accommodate the roll-in of

recruitment and matching process of the study. A total of 34 patients and caregivers attended 11 mentee focus groups meetings. A total of 11 patients and caregivers attended three mentor focus group meetings.

2.2 Thematic Analyses

Each of the focus group meetings were recorded and subsequently transcribed. The three facilitators met in-person to prepare for the thematic analyses and to ensure all had the appropriate data. The facilitators identified the salient themes from the focus group transcriptions separately after the majority of the meetings were transcribed. The facilitators gathered the strong themes after thematic saturation and had a final discussion. They concurred with the three significant themes.

Chapter 3 Results

3.1 Mentee Focus Groups: Process and Summary

The focus group discussions were held separately for the mentee and mentor participants throughout 14 months. As each mentee-mentor partnership was completed, mentees were invited to attend a focus group at the times allotted for them during the 14 month time period. Both patients and caregivers were invited to the focus group discussions. The mentees invited to the focus group discussions communicated with their mentors for at least one month. To accommodate proximity, transportation, and treatment times, four locations in central Pennsylvania were arranged for the mentee focus group participants: the Kidney Foundation of Central PA, Penn State Health (College of Medicine and Hershey Medical Center), and the Fresenius Kidney Care clinics. The focus group meetings held at the two Fresenius Kidney Care clinics were approved by the social workers. Six to ten mentees were invited to each meeting, and an average of 3 mentees attended each meeting.

3.2 Mentee Participants and Demographic Variables

The mentees (n=34) that attended 11 focus group meetings through the course of 14 months (Table 3-1) consisted of 32 patients and 2 caregivers. These 34 mentees were allocated to their face-to-face and online interventions, and they were matched with their mentors at least for one month. 20 mentees were in the face-to-face intervention and 14 in the online intervention that attended the focus group meetings. A total of 13 females and 21 males participated in the discussions. The majority of mentees were receiving in-center hemodialysis treatment (n=27) while four patients were on peritoneal dialysis and one individual was receiving hemodialysis treatment at home. Out of the two caregivers that attended, one was the wife of a patient on peritoneal dialysis and the other caregiver was a hired aid for an in-center hemodialysis patient. The average and median ages of the mentees was 53. The majority were from the city of

Harrisburg, Pennsylvania (n=20) while the rest were from throughout central PA: Camp Hill, Dauphin, Duncannon, Elizabethtown, Lebanon, Newport, York Haven, and Ephrata. 20 mentee focus group participants considered themselves to be black or African American and 12 considered themselves to be white. Two mentees that attended the meetings considered themselves to be Hispanic, Latino, or of Spanish descent.

3.3 Focus Groups: Thematic Analyses

Face-to-Face Interaction was Preferred

Out of the 14 mentees allocated to the online intervention and 20 allocated to the face-to-face intervention, the majority of the mentees expressed that they looked forward to meeting their mentors one day (Textbox 1). Moreover, many mentees felt they would like to communicate with their mentors in-person to develop a stronger relationship in comparison to phone or online communication. Some of the mentees suggested they would like to go somewhere to eat, while some of the online participants suggested meeting their mentors in-person at least once before online communication. The mentees that emphasized the importance of communicating with their mentors in-person tended to be older in age. Six online mentees were under the age of 42 and seven over the age of 41. With the exception of two mentees, mentees older than 41 emphasized the quality of a face-to-face relationship, found more issues with the online platform, or suggested meeting in-person more than the younger age group:

I just go into messaging, we just strictly messaging. I mean I check my emails 50 times a day, I'd rather do emails or talk to somebody once a week or something on the phone, like I said, I think a program where I can call somebody and get to know somebody and if they have problems or I have problems, I have that, I guess I thought maybe more of how it was at first, it was more of a social, you get to interact with people. [Focus Group 11, Online Participant 1; FG 11, OP1]

I like his idea, <meaning OPI's idea>, I mean just a one face to face meeting. Like if I came here and he was my mentor, would give me an idea. Would put a face to a name. Instead of, I know his name is, <named mentor> but I could picture him in my mind. Just a little more personable. I mean if the person is willing. Maybe the person isn't willing to do that. I understand that, you know people have their privacy and they don't want to, but it wouldn't be a bad idea, I don't think. I think it would help a little bit and open it up a little bit more. Just get to know the person just a little bit. Not saying you have to

come over to my house every night or talk to me on the phone, but this way I know who I'm talking to. [FG 11, OP2]

I don't know about other people but I think I pretty much agreed to anything with you about face to face or phone or whatever but one thing that may have helped with the whole beginning, is for us all to meet. [Focus Group 11, Face-to-face Participant 1; FG 11, F2FP1]

Facilitator *As a group or one on one?*

mmm hmmm. The mentors and the mentees. Wouldn't that be nice? Then I would see a face to the person I'm talking to on the phone. I would like that. [FG 11, F2FP1]

Facilitator *Yea, that does help us plan how that anticipation how that initial interaction...*

It would take away that stranger. [FG 11, OP2]

Facilitator *Anxiety.*

Yea, assuming they want to do that, some may not be comfortable doing that. [FG 11, OP1]

I think my mentor would be, for sure. But because she seems very friendly and personable, you know? Yea, it would have been nice to have a definite, ok, we're going to be here 1:30p as a group, like I asked you, are we all meeting together, remember? [FG 11, F2FP1]

I'm not saying it's better or worse, the individual thing is real good I think but a group thing is a good thing. [FG 2, OP1]

Facilitator *Kind of like what we're doing right now in this group?*

Focus group, yea. [FG 2, OP1]

Like I said, I think mine has been helpful with the situation I was in at that particular time. But I'm waiting to meet this individual. You need eye to eye contact with somebody, you can feel that lie come out. <laughter>. They've got too much time to think. [FG 2, F2FP1]

I sometimes wish we would have more groups, one on one, and meetings with people. I think that's very important because you can go online, but you don't meet who you're talking to. Like, I meet these two people, now you create a bond just between somebody because their going through something you're going through. So, I know how they feel. I do the in-home but I know how it is and there's so many people waiting. I met people here, like the one guy is going for his third kidney transplant. [FG 5, OP1]

Anytime you write, you don't know how the person's actually feeling. If you have a text or if I send her a text and write the text and I say a text, it's going to come out two different ways. But she knows how I'm feeling when I'm saying it verses when I'm typing it. She doesn't know how I'm feeling. [FG 5, OP1]

Two black or Africa American females in the older age group did not express the need to meet their mentors in-person, making them outliers for the older age group. It should be noted that one

of these females later completed the mentorship training and the other was considering the training. They found the program and interventions overall beneficial:

Facilitator *So, guys, switching gears here, so what were some positive aspects of the program?*
I think, for me, man I appreciate these ladies right now already, man, cuz, I am beginning to get a different look and one of the things I like about this is you have someone to talk to. [FG 9, F2FP1]
You're not the only one going through it. [FG 9, OP1]
 Facilitator *You feel that with your mentor?*
Yea, you're not alone and you get to vent and share what I can't share with my husband and daughter. [FG 9, OP1]
The mentor, that's what, uh, the mentor is, that's what I thought the mentor was that you have some outlet now. [FG 9, F2FP1]
Yeah. [FG 9, OP1]
You don't have to, uh, like you said, you can say some things to your wife and husband [FG 9, F2FP1]
They don't get it, maybe or understand. [FG 9, OP1]
But sometimes you need the person that has been through it. [FG 9, F2FP1]
Yeah, yes. [FG 9, OP1&OP2]

The online mentees under the age of 42 casually replied that they would like to meet their mentors one day and would like some in-person events similar to the older participants. However, the majority of the younger mentees did not emphasize the importance of in-person meetings as much as the older participants. Three black or African American individuals in this younger age group were completely satisfied with the online platform as a means of communication with mentors. The three patients enjoyed the journal feature and the ability to quote online, as opposed to the other mentees that were preferred to receive more advice:

It's been a little bit more for me than what I expected. Even though I haven't gotten to work closely with my mentor, [cough], excuse me. The tools that the site offers like the journal, the tracking and everything, made it worth the investment of my time. It's something I'm glad I invested in. It's something that I'm glad (stated RA's name) came and told me about and I'm happy with it. [FG 3, OP1]

It changed a whole lot. Him giving me support and also outside my family between here and DC, so that's been a big positive change for me. A lot of support for the last year and a half since I started. [FG 3, OP2]

When I'm on it, uh, I've been feeling good, so all my, I guess my response has been good towards it but, uh, if somebody is having problems, it's definitely a good program to use because it's somebody to talk to. Because everybody doesn't have somebody to talk to. [FG 5, OP2]

Anytime you write, you don't know how the person's actually feeling...She doesn't know how I'm feeling. [FG 5, OP1]

Facilitator *You're right that, that either, whether it's said in a cheery way or sarcastic way, it might be exactly the same words but very different feel. Are you feeling similar things with the typing, uh...*

I'm fine with it, I mean, cuz, it does have your feelings like, it's a picture, yep, I guess kind of helps with your message. Kind of does. [FG 5, OP2]

I think the website is kind of like, it's good, cuz everything you need on there is on there to let you know how you're feeling so, I guess it's good. [FG 5, OP2]

Yea, it's pretty self-explanatory. [FG 5, OP1]

The younger caregiver mentee, a hired aid, on the online platform was dissatisfied with the responses from her mentor and explained that her mentor's advice was the main hindrance to her website use. Additionally, she found the website's format to be misleading as a caregiver and would be better suited for patients:

Yea, like even just a little paragraph blurb like this is my experience, this is what I've been faced with and regardless of whether it's for the patient or the caregiver, it's just gives, if we each have a little profile we could kind of go on to like ok, so this is who I'm talking to. It's not just a faceless, nameless kind of in the shadows person that you don't really have a real attachment to. [FG 4, OP1]

I think too, if it is an aid, I know that in my profession, we're kind of like trained to do and say certain things. We're supposed to have certain mannerisms, we're supposed to say and do like you know, kind of what's in the book, you kind of keep to it because that's like what your taught and it's tried and true so why not stick with it. But you know in my case where I used this experience as like, you know, something that was kind of more personal to kind of get that it's the cookie cutter, very text book kind of answer back, that wasn't realistic to me. It didn't give me that hope I kind of reached out for and so like I think that to just be able to have somebody who has more of an opinion or more of an output then just to like, I could have gotten that same inspiration by reading something in a book. I've done training. I know what I'm supposed to feel then when I'm not feeling like then I need somebody to be able to be like, it's ok, but this is how I got through it and that's why and that's the kind of mentor I was expecting and I hadn't received that. [FG 4, OP1]

Although she was critical of the website and her mentor's advice as a caregiver, she did not mention the desire to meet her mentor at the meeting and found her mentor provided a limited support structure. There were two younger mentees that also expressed that they were not fond of the website's structure. One of these individuals found the mentorship useful, impacted his quality of life, and did not find the mechanics of the website a hindrance to benefitting him:

I have some issues with that. I used to get on online for the mentor program. It was going good at one minute then the next minute it was broke down and they was telling me I had to resign my name and everything else and I just got frustrated. [FG 8, OP1]

Facilitator *OP1 is there anything we can do better to help make your mentorship better?*

I guess like OP2 was saying about a website would be more sufficient. [FG 8, OP1]

Well, I talked to my mentor about some things and he kind of guided me through and told me some things that he was going through. We tried to find common ground. How to figure it out in a way that can help both of us at the same time. [FG 8, OP1]

The other found the website's accessibility hindered the opportunities to get in touch with his mentor further. It should be noted that he did not desire an older mentor as well, which may have affected his desire to continue using the website properly since he was matched with an older mentor. He was an outlier for the 25-41 age group:

I've sent an email to my sponsor but I haven't really had a back and forth with him yet. Uh, my only thing about that thing is, I think it should be, I know it might be hard to do it but I think it should be an app where if I do send him message to him, like my phone will tell me, hey I got a message back. Makes it so simpler especially if your super busy or if you're on dialysis and you don't have access to a computer and your phone just beeps and like oh, how are you doing and you can just go back to focusing on whatever you're doing. Having to find a computer and get on the website or even trying to get on, like the way they have it now, if you get an email from your sponsor it will email it to you and that's the same thing it's just getting an email to the same website. Basically the same thing, it's just if I could just get something that pops up on my phone, hey, you've got a message. [FG 8, OP2]

That would be a lot easier. [FG 8, OP1]

I haven't really talked to my mentor yet. But somebody I could talk to openly that's really for young people, uh, a mentor around the same age going through the same because it's much harder to talk to somebody older. It's like getting talked to by your Mom. I need somebody I can relate to. I can be candid with. If something's going wrong with me, I can speak to them on a level that we're the same, instead of like yes sir or yes mame. [FG 8, OP2]

Therefore, the males in the older age group that were using the online platform were less satisfied or desired at least one in-person mentor meeting than females. These five older males were over the age of 41 and the majority were black or African American on hemodialysis. Only two were white males in the older group with one using peritoneal dialysis and the other on hemodialysis. The four females on the online platform, regardless of age, did not emphasize the desire to meet a mentor in-person as much as the males that were using the online platform. These four females

were black or African American and on hemodialysis with the exception of the white female caregiver. The younger mentees generally said they would like to meet their mentors but did not emphasize as much as the older mentees. Four out of six of the younger mentees on the online intervention found communicating with a mentor online useful. The younger caregiver found that her mentor was a part of her support structure in a limited way, and the patient that was not fond of the website's format agreed that his mentor was a part of their support structure along with the others.

Good Mentors were Relatable, Listeners, and Shared Information Honestly

The mentees provided a variety of ideals when it came to what they believe makes a good mentor when asked by the facilitator. Some of the mentees thought a mentor should be open and outgoing, likeable and kind or caring, easy to converse with, and experienced. However, the significant themes when asked what they think makes a good mentor were someone that honestly provides information, someone who is relatable and understanding, and a good listener.

A few of the participants in the older age range, specifically from 49-66, mentioned that a mentor should be a good listener while none from the younger age group mentioned good listening. There were six mentees who mentioned good listening. Three mentees in the face-to-face intervention and three in the online intervention. Four females mentioned this quality as well as two males. One of the men was white and on peritoneal dialysis, while the others were on hemodialysis and black or African American:

Facilitator *So what are some of the qualities that make a good mentor?*

What she spoke on. Having the experience. [FG 9, OP1]

Good listener. [FG 9, OP2]

Listener [FG 9, OP1]

Listening yeah. [FG 9, F2FP1]

A couple of years over you. [FG 9, OP2]

Right, because if I'm venting and booing and crying and she is sitting there listening, I'm able to get all that off of my chest. [FG 9, OP1]

Right. [FG 9, F2FP1]

Facilitator *Ok, good. So, and this might be a tough question, but even within kind of the online mentorship, what are some qualities that you think make up a good mentor?*

*I think somebody willing, that has to be outgoing, willing to talk to other people
<interrupted by F2FP1> [FG 5, OP1]*

Meet strangers. [FG 5, F2FP1]

*Yea, and be able to tell how your, how you feel verses how they feel and understand that
the way that you feel may be different than how they feel. So you gotta be able to be a
good listener and somebody that is very open too, yea. [FG 5, OP1]*

*I think they should have a certain amount of questions to ask you, it could be daily or a
week, I mean, certain questions, different ones. [FG 5, OP2]*

Facilitator Like what? Give me an example.

Uh, like how much fluid did you gain today or uh, <interrupted by OP1>

*How's your blood pressure or your weight or are you keeping your diet? Stuff like that
to make sure, to maybe be, you know, if you're not afraid to say look, you know, maybe
cause sometimes you need a push, I know my daughter's a nurse, so if I do something
wrong she tells me I'm doing it wrong. [FG 5, OP1]*

A good quote of the day or something, or motivation or something. [FG 5, OP2]

Yea. [FG 5, OP1]

*Facilitator Yea, I think that's a great idea. Some way to kind of give some regular
feedback and support and inquiry to how things are going maybe beyond ok I see you got
a smiley face again but is that really a smiley face, yea. What else is going on? Why is it
a smiley face maybe.*

*Or if you're having a bad day, why are you having a bad day? Is there something I can
do for you or give you some support? Cause sometimes your family is always there for
you but that sometimes isn't enough. Like I said, sometimes my kids don't understand.
They think maybe that, because they don't have to do it, they go through, you know that
the only way you stay alive is to have this so a lot of times they don't understand that
you're going through it. There's days I don't wanna hook up to the machine, you just
don't want to do it. You have to do it. I'm sure there's days you don't wanna go, you
know you have to take those hours out of your day, your time and do it. [FG 5, OP1]*

Facilitator Ok, so what are some qualities of a good mentor do you think?

Somebody who is not afraid to share the information. [FG 2, OP1]

And a good listener. [FG 2, F2FP1]

*He likes to talk about himself and I like to talk about myself. You know how I am, I play
around a lot. I don't take nothing serious. He asked me the other day, my mentor says,
how are you today? Me? I'm just like Maxwell House. Good to the last drop. [FG 2,
F2FP3]*

*I think they have to care. They have to be a caring person about other people. Be able to
relate. I guess they can relate because they are in the same predicament or already was
in that predicament. [FG 2, F2FP2]*

Like she said a good listener too. [FG 2, F2FP2]

Seven mentees found understanding and relatability to be some of the qualities of a good mentor. Three were in the online intervention and four mentees were in the face-to-face intervention. Unlike the quality of good listening, there were some mentees in the younger age group that mentioned similarities to relatability or understanding. There were two younger mentees, including the caregiver, and five in the older age group counted for this subtheme.

Across all age groups, there were only two males that thought these qualities were important and the other five were females. Three were white, two females and one male, and four mentees were black or African American. All of these mentees were on hemodialysis with the exception of female caregiver, who was taking care of a mentee on hemodialysis, and a male peritoneal dialysis patient:

Facilitator *So the interaction has been limited but what do you think would be some qualities of a good mentor?*

I think that being able to have somebody you can really identify with like because I'm not personally a dialysis patient, when I go on and kind of using it as like a journaling experience, I'm kind of just like venting it off, it is nice. It would be nice to have somebody else to identify with and I don't feel like the mentor was like really giving me that fulfillment. [FG 4, OP1]

Facilitator *Ok, good. So you mentioned the things about the personal interaction, personal stories, personal situations as well.*

Yea. [FG 4, OP1]

Facilitator *Then as well. Ok.*

Facilitator *So what do you think some of the qualities of a good mentor would be? [stated OP1's name]?*

For me a good mentor is somebody who is patient. That's like the number one skill at being a mentor because in high school when I mentored some of the younger classmen who like just go through high school, one of the most important things was to understand when your mentoring somebody, it's because they don't quite understand everything you do so you have to be patient until they do. So, if I have a bad day or I just fly off the handle and I'm just upset and I'm venting to my mentor, a good mentor is going to understand and say ok, this is going to happen but this is how we can deal with it. This is a good way to deal with it or if you do this, this might not turn out so good so it might not be a good idea. But in the same time, be confident enough to help me feel confident that it's going to be ok. [FG 3, OP1]

Facilitator *So are there any other words that would describe the good qualities of a mentor? You mentioned patience and confidence. Anything else?*

Patience, confidence, compassion, um but strength because sometimes we can lean on a person so much they have to tell us no. So they got to have strength. [FG 3, OP1]

What about you [stated OP2's name]? What are the qualities of a good mentor?

Um, the strength, the compassion, the patience and they got to give them kindness. Kindness as well. To their courtesy, it's their time and that's about it. [FG 3, OP2]

Understanding what you're going through. That's the main thing, that you can talk to someone that they can relate. [FG 7, F2FP1]

Facilitator *So does she talk to you about her experiences about dialysis?*

Oh yea, and about the kidney and she was telling me, because I was thinking about getting a kidney and all that and she was telling me that if I did decide to get a kidney that I do have to take a lot of medication. She told me she had to drink a gallon of water almost a day and she said, you know I have to take medicine and let me know. Through it

all, she still, has her like her down days, she let me know, you know. So if I decide to hop up and get a kidney like it ain't going to just be all sunshine. [FG 7, F2FP1]

Facilitator *<laughter>*

So that's when I kind of just, you know, say well 6 in one hand and a half a dozen in another you know. [FG 7, F2FP1]

Someone who communicates with you. Share their life experiences. Present, past. The guy I got, me and him like I said. Any military person, I don't care, Army, Navy, Airforce or Marines, if you meet up with someone who had that past experience you automatically click. When I was in the military I had all kind of Airforce and Army friends... [FG 1, F2FP1]

Lastly, ten mentees from ages 45-73, emphasized sharing information and honesty to be qualities of a good mentor. Some mentees gave examples such as talking about experiences or holding a conversation to be important. The majority that felt this way were in the face-to-face intervention, hemodialysis, and were male. Again, none from the younger age group emphasized this quality. Only two online mentees mentioned this as important, while the rest were face-to-face and in the older age group. Eight males and two females felt gathering information from a mentor to be important. The two females were white: one was on peritoneal dialysis and the other on home hemodialysis. Four males were black, three males were white, and one male considered himself to be Hispanic, Latino, or of Spanish descent:

Facilitator *So what do you think are some of the good qualities of a mentor? What would you like your mentor to do? Do they do it or not?*

I would say tell me the truth. [FG 8, F2FP3]

<group laughter>

Be open [FG 8, OP2]

Facilitator *Yea, good.*

I think this lady just says it how it is. She's really nice. [FG 8, F2FP2]

So far, we don't have long conversations. We do a little at a time. Each time we talk, we collect more information. [FG 8, F2FP1]

Facilitator *So a little bit at a time?*

Yea, a little bit at a time. So far he's been pretty good with letting me know, you know, because our conversation isn't that long but it's long enough to where we get information from each other. Each time I learn a little bit more about him without bombarding with a lot at one time. [FG 8, F2FP1]

Facilitator *So what are qualities of a good mentor?*

When you ask a question, your honest opinion and your honesty. [FG 11, F2FP2]

Facilitator *Honesty. Ok. Others?*

Personable and willing to share. [FG 11, OP1]

We talk like friends. Like she was going away to Virginia last weekend and you know, just things like that. [FG 11, F2FP1]

Facilitator *So how well has your mentor appeared for this project and are there things that person does really well, how could we have helped that be better? Does your mentor seem prepared to be a mentor?*

Yes, I mean, I think, I can basically talk to her about anything. And in turn she can talk to me about anything. [FG 11, F2FP2]

One that does a lot of explaining, because this is new for me, so and he's been there for a while. The more he talks the more experience you get understanding stuff. [FG 10, F2FP1]

More outgoing, more discussion back and forth between the two, um, again I felt as, um, family was more important which, you know, I sense that's true but it didn't involve the setting aside time for discussion with other things about other things. So I haven't been in contact with him for two or three weeks now simply because I've been in the hospital dealing with eye conditions here. He did seem interested in knowing more about my situation and uh, but he didn't really explain much more about him. [FG 10, F2FP2]

There was more variability in the younger mentees when asked what makes a good mentor compared to the older mentees. There were less common themes within their age group as opposed to the older participants.

Mentorship Program Can Provide Support

Each mentee had their own expectations of the mentorship program. Although there were only six individuals under the age of 42 in our study, the majority found the program supportive. The mentees were asked if their mentor was a part of their support structure or the mentees mentioned their appreciation for the program on their own during the meeting:

I talked to them, but it wasn't like we weren't on the same time to talk back and forth so it was like a message and then later he'll read it and I'll read his. That's how it was. [FG 5, OP2]

Facilitator *Any other ideas of how we could improve that relationship? I'm not sure right now. <laughter> [FG 5, OP2]*

Even if I heard from, even if I got a phone call or something you talk to the person, you get more personal. [FG 5, OP1]

Even the younger caregiver who was disappointed in her mentor's responses found her mentor to be a limited part of her support structure and found strengths in the program:

Facilitator *Good. Ok, I think you've given me a lot of good ideas about the mentorship. Do you consider your mentor to be part of your support structure? Yea, I mean in a way because it's nice to know that when you have somebody that can be there. If I wanted to use the site as somebody to just have a conversation with, it's nice to know that that outlet is there. But, you know...* [FG 4, OP1]

Facilitator *It's limited.*
 Yea. [FG 4, OP1]

Facilitator *Ok. Uh, so what do you think the program can do to help strengthen this mentor/mentee relationship? I think, honestly, I think this could be really an awesome thing for a lot of people. I think it, even more than just, I know there can be different things that can be offered like the face to face, the meetings and things like that with the mentor, I think that could be really great for a lot of people. I think it could have been really great for me if it would have been a little bit different of a situation. I think, really just encouraging a little bit more communication or I don't know doing like a profile or something with the people that you bring into the program so that way you can kind of match them a little bit better. Based on personality or just kind of giving them somebody they can identify a little more with. And that way it's more of a, um, a better situation that you can kind of bounce off of somebody that has really been there and done that kind of thing and it's not just your just stuck with any person that doesn't necessarily know what you're going through.* [FG 4, OP1]

When it came to mentees' quality of life under the age of 42, many found the mentorship program impacted their quality of life, with the exception of the caregiver and possibly the male patient:

Facilitator *[stated OP1's name], do you consider your mentor a part of your support structure?*

Yes I do. [FG 3, OP2]

Facilitator *Yea, good. Are there other people that are in your support structure as well?*

My dad. My step-mom. When I'm down there, I try, we try different recipes. I found a couple in yesterday's paper and in the grocery store, but I try and make the recipe myself. [FG 3, OP2]

Facilitator *So what about you [stated OP2's name], your support structure, who's in your support structure then?*

My family... [FG 3, OP1]

Facilitator *So has it impacted your quality of life?*

I go to church more. I get involved with other people. I would like to someday tell the little kids what your kidneys can do to you and explain to them... [FG 3, OP2]

Take care of them now. [FG 3, OP1]

Take care of them now. [FG 3, OP2]

Facilitator *Good. Good. So what [stated OP2's name], what can the program do to make that mentor/mentee relationship stronger and more effective?*

Um, Um... [FG 3, OP2]

Facilitator *What can we do to help that out?*

Give me the strong points and what the weak points are, what not to do. [FG 3, OP2]

Facilitator *So are there any particular weak points you wished we had addressed? I know earlier you mentioned some things that could be done differently. The way I'm eating, would be some. Try to pass on to somebody that's doing it right now that needs to follow, follow the restrictions of the fluid and the eaten. Change the eaten habits. [FG 3, OP2]*

Facilitator *Ok, good. [stated OP1's name] what could we have done differently to make that mentee/mentorship relationship stronger and more effective? I don't think there is anything that the program itself we need to change to make it stronger, I think you just continue hiring people who want to be there. Just continue to hire people who have the common goal of helping somebody. Just stay on that path. [FG 3, OP1]*

Facilitator *Ok, very good. Has this mentorship experience been what you expected and why or why not? It's been a little bit more for me than what I expected. Even though I haven't gotten to work closely with my mentor, [cough], excuse me. The tools that the site offers like the journal, the tracking and everything, made it worth the investment of my time. It's something I'm glad I invested in. It's something that I'm glad (stated RA's name) came and told me about and I'm happy with it. [FG 3, OP1]*

Facilitator *What about you [stated OP2's name]? The last time I talked to (stated Mentor's name) was in the beginning of January. It's been very helpful and hopefully I can get in contact with him when I leave from here and tell him how the focus group went. [FG 3, OP2]*

Facilitator *So do you consider your mentor a part of your support structure? <group answered yes> [FG 8]*

Facilitator *Anything else specific to what your mentor has helped you do? So kind of summing this up a little bit. Has the mentorship impacted your quality of life? <group answered yes> [FG 8]*

Facilitator *So what can we do as a program, to help the relationship be stronger between you and your mentor? Like I said before, an easier way to access the mentor or the website so that you can talk to the mentor. Maybe like, uh, well you would do this with your mentor like special days, like, uh, like this date, we'll have a mentor and mentee meeting. Everyone will go out to eat. Meet each other and just get together and hang out and maybe tell stories and what not. Tight nit group. [FG 8, OP2]*

This was interesting because there was more variability in the younger mentees when asked what makes a good mentor in comparison to the older mentees. Additionally, the younger mentees were all in the online intervention, which was less well-received by the older mentees. There were with four males and two females in the younger category. They were all black or African American patients on hemodialysis with the exception of the white female caregiver.

Unlike the younger age group, five mentees over the age of 41 answered that their mentor was not a part of their support structure and did not impact their quality of life. These participants consisted of two white females, two white males, and one black or African American male. One white mentee was in the online intervention while the rest of the mentees were in the face-to-face intervention. While the majority were in the face-to-face intervention, these older mentees wanted even more communication and interaction. They were all on hemodialysis, one of which was on home hemodialysis:

Facilitator *Do you consider your mentor to be part of your support structure?*

<group answered no, not really> [FG 11, OP1]

Unfortunately no, only because I've not, we've not been able to really connect in all of these months, connect on a like we both want to do face to face but we've not been able to do it. It's just been one thing after another in my life and in hers. And that's unfortunate. [FG 11, F2FP2]

Facilitator *Has it impacted your quality of life?*

<shaking head no> [FG 11, F2FP2]

<group – all answered no> [FG 11]

In the sense that he answered questions, maybe a little bit since he answered questions, I didn't, more concisely then it would have otherwise, but other than that no. [FG 11, OP2]

Facilitator *Ok. So do you consider your mentor a part of your support structure?*

I really don't, I find he's part of it but not as deep into it as I was hoping he would be. I was hoping he would be into exchanging information. [FG 10, F2FP2]

Facilitator *So do you think he's committed to the mentorship you think or semi, I guess?*

Uh, sometimes yes, sometimes no. Depends on the subject is, he's interested in my current situation and would like to know more about the tremor control and stuff like that but as far as himself, he doesn't seem to want to be giving out too much. [FG 10, F2FP2]

Facilitator *Ok. Interesting.*

[Mentor's name] was very thorough about everything. He wanted to know more about me and stuff like that. I liked him. [FG 10, F2FP1]

Facilitator *And how has the mentorship impacted your quality of life? Has it?*

Hasn't it?

I think it made me think about a lot of stuff. Something I, if I didn't know the answer or something, he could explain it to me and stuff and I think it really helped me understand. [FG 10, F2FP1]

Facilitator *Like dialysis related things?*

Yea. What to look forward to about kidneys and stuff like that. [FG 10, F2FP1]

Mine relationship didn't bind that much on the physical aspects of the dialysis it was just more superficial. [FG 10, F2FP2]

Facilitator *I see. Ok. So you didn't really talk about renal topics or anything like that so much?*

No. [FG 10, F2FP2]

See, mine did. [FG 10, F2FP1]

Facilitator *Ok.*

Facilitator *Ok, good. So (stated name), has your mentorship helped you, has it been more involved with your own care? Has that person...*

No, and that's probably my fault. A lot of my fault. Being active in other stuff. [FG 4, OP2]

In one meeting, the questions of support structure and quality of life were not directly asked due to the fluid discussion. One of the mentees expressed his thoughts of the mentorship program and communicating with a mentor. He was black or African American and was on peritoneal dialysis:

I'm not saying that I don't need no mentor, I never ruled that out, but I take my experience and what I went through to where I'm at today and that's what's going to help me more mentally because that's the time like just going to work and not knowing what's wrong with me for two or three weeks and the guys would have me go in a room and just lay down. That's all I could do is sleep. They said, we got it and they did it for two or three weeks. [FG 1, F2FP2]

So it's time to get our mentor to reach back out to us [FG 1, F2FP3]

Facilitator *I think so, I think that would be good and I hear what you are saying you had this experience and can imagine how that's influenced but I'm going to have to take your wife's side on this. I think that talking with the mentor that might be something we would love to hear and if it's not, you can let us know that too.*

Ok, yea. [FG 1, F2FP2]

Facilitator *You know, that is the point of the program, is to try to see if this helps. Like I said, you know, just for me, personally I'm not going to rule that out. I don't have a problem sitting down listening to someone but still though I feel that what I'm experiencing going through today in life, I need someone to be on the same level because this is my second time around and to go back through this again, I need someone*
<interrupted by F2FP1>[FG 1, F2FP2]

That's why I said the more people we have here we can all learn something. [FG 1, F2FP2]

There were participants that did not answer the questions or were not asked the questions at the focus groups; however, these participants were clearly appreciative of the program and the mentorship. These eight mentees consisted of one black or African American male, two Hispanic males, and two white males. All were in the face-to-face interaction except one of the white males on peritoneal dialysis in the online intervention. There were three females: two black or African American and one white in the face-to-face intervention. The eight participants were on hemodialysis:

Facilitator *Sure, nope that's totally fine. Do you feel like, again, I know you're early in the process with your mentors but do you feel like they could come part of your support structure?*

Should, yea. We're all in the same boat. <laughter>. We're all in that same boat because I made friends at dialysis. How about you <stated F2FP2's name> have you made friends at dialysis? [FG 6, F2FP1]

He's a good mentor, it's just, he's an older guy, set in his ways. I mean I respect him and I listen to him and he talks with the techs and the nurses and stuff. Cuz we sit right beside each other. [FG 5, F2FP2]

Facilitator *Are there other things that this program can do to help strengthen and make that a better mentor/mentee relationship?*

I guess, I gotta be in more programs [FG 5, F2FP2]

Be more open huh? [FG 5, F2FP1]

Yea. [FG 5, F2FP2]

Yea, I think you said something at the end now when we're done with the program or the mentor is, if we could meet our mentor. [FG 5, OP1]

[Mentor's name] has been really good so I don't know that he could give me any more information than he's already given me. Now, it's just a matter of what pops up from time to time but I'm not having any trouble with the machine. No trouble getting supplies. He just stays on me about what meds I should be taking. He's good like that. [FG 1, F2FP4]

Before I met my mentor, I was curious of what he could give me in the way of practical information and the first thing he said to me was make sure you have enough supplies to get through a winter snow storm, which I haven't even thought about so now I'm trying to sneak a few boxes ahead which I'm slowly getting to. My wife is a registered nurse and steers clear of me. The first time we hooked up to the cyclor, she missed a page in the book, <laughter>, so I was like go away and leave me alone. I'll do it on my own. But, like you, did you take your medicine, are you drinking too much fluid, <laughter>. My mentor is, my wife says, he is my alter ego, <laughter>. We both like the same sports team and both are politically conservative...He has been really good. [FG 1, F2FP4]

That's what I'm saying, having her doing it, they've researched your background information and that's how they're connecting you so your mentor your picking are compatible. [FG 1, F2FP3]

Facilitator *So, <stated F2FP2'S name>, tell me a little bit about your experience. Have you connected with your mentor at this point?*

Um, Not too many called last week. I had a call for the blinds commission and I guess, yes, my mentor called me and wanted me to um, maybe this week. [FG 6, F2FP2]

Facilitator *Ok, what did you guys talk about?*

No. No. No, we're going to have a meeting. He just called me and told me to go out and meet and talk and I haven't talked to him. [FG 6, F2FP2]

Facilitator *Ok, so you just connected to kind of touch base and arrange a meeting. Ok, great. Did you set that up?*

No, not yet because I'm been over fluid, over <garbled>. I was kind of sick and then my doctor told me I had to make urine the water that I drink. I keep doing it and no, no, you're good. So that's why I don't have to make, to go outside. [FG 6, F2FP2]

Facilitator *So you haven't had a chance to meet up with your mentor yet?*
 No. [FG 6, F2FP2]

Facilitator *Ok, so what are some of your hopes for what that mentors, this could be for either <stated F2FP1 and F2FP2's names>, what are some of your hopes for what that mentorship relationship would look like? How could a mentor help you?*

Um, to this point, I don't know. I mean, um, how do I tell you this, um, I guess I don't feel depressed, I don't feel like that. I feel happy all the time.. So it's really tough. But even with that, you know, I feel good. I feel happy. Sometimes you, mentor way he can help me, I don't know, maybe advice you know, about what I can do to do better. [FG 6, F2FP2]

I tell you, I like my mentor, I like [Mentor's name], he is pretty good. [FG 2, F2FP3]

He comes every other week and he's a nice person I can say that. The only thing, like I told you, he has an oxygen tank and he has to cut it short because he lives in ...and he comes all the way to [states city] to visit me. He has to cut it short sometimes because I told him get a 100 pound tank. <laughter> [FG 2, F2FP3]

My partner is pretty good. <F2FP1's coughing>. He comes over every other Saturday to visit me and we talk and we exchange ideas and opinions, < F2FP1's coughing>. [FG 2, F2FP3]

Mine's phoned, so, um, we talked 23 times its been now. She seems to know what she's talking about, ya know? [FG 5, F2FP1]

We were going to set up a plan, excuse me, um, we were going to set up a plan, a date and we was going to a restaurant to eat. [FG 5, F2FP1]

Facilitator *That's really neat to hear you give that feedback because we hear that somebody after each one of these focus group, but we also hear it from the mentors during theirs. So even the folks that are, you know, experienced and you know, volunteering to work with each of you, they tell us the same sort of thing. It really is a benefit to hear other people's stories. So I'm glad that piece is helpful. It's helpful to the program to hear that because we can look for ways within the program to integrate that. Yea, more interaction. [FG 5, OP1]*

Facilitator *Particularly for folks who are doing home dialysis where you don't have, you know, kind of the in-center experience that you get to sit next to your mentor in the chair, so that's a little bit different level of engagement.*

Yea. [FG 5, OP1]

Yea. [FG 5, F2FP1]

Facilitator *Alright, well if you think of any thoughts outside of this, you know, please let us know. We're very open to what you're thinking and how we can continue to make the program better.*

I think if you guys just keep growing and doing what you're doing, I think it's going to be better, because it's a big help, and like I said, I would like to meet my mentor or talk to him, or you know, because I think that's important. [FG 5, OP1]

One hemodialysis mentee [FG 11, OP2], white and on the online platform, explained that the mentorship program was what he expected even though the program only slightly impacted his quality of life. Although his mentor was not a part of his support structure either, he was generally satisfied with the program:

It met my expectations. This is what I expected. I asked a question and he would answer as best he could and that's all I was looking for. I wasn't looking to make a new friend in the sense that to tell him what my day was like, that's not what I was looking for. What I was looking for was with I have, I'm happy with it. If I can get the website to work right. <laughter> [FG 11, OP2]

Facilitator *So have there been any positive aspects to the program? Have there been other positive aspects you want to mention?*
I think the whole thing is positive. Mine has been a positive experience, it's the website I have a problem with. I don't have any problem with the mentor themselves. [FG 11, OP2]

Four mentees found the program did not impact their quality of life but their mentors were a part of their support structure. They were all black and on hemodialysis, two males and two females. Three of these mentees were in the face-to-face intervention and one male was in the online intervention:

Facilitator *Ok, good. And do you consider your mentor a part of your support structure?*
Yeah, [FG 9, OP1]
Oh yeah. [FG 9, F2FP1]

Facilitator *So that's everybody. Anybody else? So do you consider your mentor a part of your support structure would you say?*
Well sure. Before that it wasn't too many. I mean like she said, she knows my brother and he's going through it but he's my oldest brother and I'm the youngest and there's a big gap between there. We can talk about this but that's about it. But it's different talking to somebody else about it. [FG 2, OP1]
Yea. [FG 2, F2FP1]
Yea. [FG 2, F2FP2]
But I can get a lot of information from him but I'm just saying with this here though. Then everybody that has a disease is not going through the same thing either. That's true at the same time. [FG 2, F2FP1]
It's just the same disease. That's all. [FG 2, OP1]
You know sometimes your family says they are going to support you but they don't really give a <cursing> about you. [FG 2, F2FP2]
I think they do. [FG 2, F2FP1]
I don't think they understand. [FG 2, OP1]

I talk to a lot of people that their family members come home and the first thing say yea man that dialysis take a whole lot of ya don't it? I say, wait a minute, speak for yourself. I try my best not to go to sleep when I go home. Because If I go home and crash then I have to get up and I have to eat and then when I'm up, everyone else is going to sleep. So I try to stay up and keep myself active even though I'm tired. I try to be active and everyone in my building is still out and I can go around and talk and then go in and go to sleep. I live in a senior building. [FG 2, F2FP1]

Although two mentees did not specifically express how the program benefitted their quality of life or how their mentor was a part of their support structure at the focus groups, these two mentees eventually joined and completed the mentorship program. Both were black or African American. The female online mentee was attending the training at the time she was participating in the focus group. She was passionate about the program and was advising a fellow mentee during the meeting:

And that kind of thing. It's the job of this individual to direct you to the right individuals, once again in this entourage so that's why I'm saying to you in reference to learning as much as you can so that this entourage is not, they control it, but they're not totally in control. Ok? And that's going to empower you and then as you and this coach, because you're going to have daily struggles, and then you and this coach are going to try to work these daily struggles out. You know what I mean? From what I'm understanding from this reading I'm doing, is I as a coach am not going to be able to say, you should. That's not going to come out of my mouth. [FG 9, OP2]

Right. [FG 9, F2FP2]

Right, cause if you drink too much today, she's not going to tell you that you shouldn't drink. [FG 9, OP1]

I'm not going to tell you that you drank too much. [FG 9, OP2]

You know. [FG 9, F2FP2]

Right, right but I'm going to share an experience, my experience, ok? And then maybe in sharing my experience it may enlighten you. [FG 9, OP2]

That you'll know not to drink too much. [FG 9, OP1]

Other than that, I'm going to say to you that if for example you know, you're potassium is completely out of whack and you're having some heart issues, I'm going to direct you to somebody in this entourage that's going to help you. [FG 9, OP2]

Right, cause what you're saying is and that's one of the things I've been picking up now, what you're saying is, you are responsible. [FG 9, F2FP2]

You can do it. [FG 9, OP1]

Even though you are sick, you're responsible. [FG 9, OP2]

You can do it. [FG 9, OP1]

Even though it's hurting, you're responsible. [FG 9, OP2]

You can do it. You're your own cheerleader. I wrote on my mirror... Once I made it through that surgery, I mentally now have to now, ok, He's got me living for a reason but they prepared me that the ... could come back and put that on a back shelf. But I was able to go back to work and it appeared a couple of months later and they pulled me back out

and I've been out ever since but mentally, you really have to work on yourself to keep fighting for yourself to believe in yourself. [FG 9, OP1]

And then when you have these lows, you go to your mentor . [FG 9, OP2]

There you go. [FG 9, OP1]

You go to your mentor and your mentor pulls you out of these lows or helps you get out of these lows. Cause you're going to have them. Don't think you're not, ok? [FG 9, OP2]

You have to find that quality of life, this is what your mentor is for. Vent all that out. Go home and try to have fun. [FG 9, OP1]

Vent that out. The closer they are, like for him two years, if he could get a mentor like five years like me, you know what I mean? I know where you're at, I have been where you are at. I've fallen off the table, picked myself back up. If I would have had a mentor then, I would have wanted a mentor a little closer to me that could have, you know, put it all into perspective for me real quick. [FG 9, OP2]

The second mentee, male in the face-to-face intervention, had ambitions to be a mentor from the beginning of the study:

I don't think a mentor should or could be telling you what medications to take because they're not physicians. And I as a 30 year medical person, I don't tell people what they should take. You have a doctor to tell you that. [FG 1, F2FP1]

Six mentees found that their mentors were a part of their support structure and the program impacted their quality of life. Two were white mentees, one male and one female. There were two black or African American females and two black or African American males. With the exception of one black or African American online female, the rest were in the face-to-face intervention.

One white female was on peritoneal dialysis while the rest were all on hemodialysis:

Facilitator *So, how has the mentorship impacted your quality of life?*
Just being able to vent and being able to get those things that you're not sitting in the dark all the time or upset that, you know, you had a bad week or I go to dialysis Monday and I get sick on the machine and I didn't like that they pulled too much and I got an attitude and I don't feel good, I'll come home and I'll say to my husband, I got sick on the machine today and he says, you ok? I say yeah, I'll lay down but I don't mentally go through what I really want to say to him about them people there they don't be doing this, they don't being doing that. It's not like I want to home and vent to him about those kind of things because men take us women explaining and talking to them a little different than you telling you, my girlfriend over here what happened at the center but you know, you're wife come home and want to tell you and she's venting and nagging about what they did but I can go to the mentor and say, you know, I told them I wasn't feeling too good and they was like, well we'll do this or we'll do that where I feel, maybe they're not balancing out too well of how much fluid I don't have or didn't gain any weight, that's a really big issue with me if I don't, especially going through treatment week I'm not eating or drinking as much so when I go Monday, I haven't gained anything so what can you really take off of me. They can't really take too much, they can try to cleanse me but then

they're trying to balance me out with the fluids so, Lord help me, but I'm still here, I'm still standing, but your mentor is the one you can go to and like, really explode and vent to so that way my quality of life is better because I'm not putting it on my kids or my husband and we can now watch a movie. [FG 9, OP1]

Facilitator *And how has the mentorship impacted your quality of life? Has it? Hasn't it?*

I think it made me think about a lot of stuff. Something I, if I didn't know the answer or something, he could explain it to me and stuff and I think it really helped me understand. [FG 10, F2FP1]

Facilitator *Like dialysis related things?*

Yea. What to look forward to about kidneys and stuff like that. [FG 10, F2FP1]

Facilitator *Do you think she's impacted this mentorship has impacted the quality of your life.*

Yea, she's a nice person and we enjoy spending time together. [FG 7, F2FP1]

Mentor Focus Groups: Three Themes

The results from the mentor focus groups compliment the three main themes from the mentees. Although the five mentors in the first focus group were not matched with mentees online yet, the mentors from the last two focus groups had similar thoughts to the mentees in the online intervention. Some of the mentors expressed the benefits of the face-to-face intervention and expressed the general difficulty of keeping in touch with their mentees:

It's very difficult to deal with feelings online if you can't see the feelings, if you can't feel the feelings, they don't translate very well in text messages. Your pretty much reduced to how are you feeling? What's going on? Did you try this? Very objective type stuff and that kind of misses where most people are at if they're need help. [FG 2, Mentor 2]

Even the younger mentor mentioned wanting to meet his mentees one day, and he offered better strategies to improve the online communication similar to the many of the mentees. The second theme was also significant for the mentors because they found importance in being able to relate and share information:

I think I understand him. Maybe I can relate if I were going through what he's going through right now, particularly with the recent rejection. He wants to get off dialysis. Been on it 5 years. I just need to reach out and maybe have that face to face and say hey let's get to know each other better and see how that works. [FG 2, Mentor 1]

The third theme was the emphasis of support and how to provide that support to their mentees as the mentors of the peer-mentoring program:

And it's support. Like I said, I'm just here to help you going through what you're going through and any questions. I've experienced some of the things you're going to experience. [FG 2, Mentor 2]

Chapter 4 Discussion

4.1 Summary

Face-to-face interactions were preferred because the participants found it facilitated more meaningful partnerships, particularly more than online or phone communication. This theme was significant in participants over the age of 42 in comparison to the younger participants. The younger participants did not consider it necessary to meet their mentors in person as strongly as the older participants, and females in the online intervention did not emphasize the need to meet their mentors in person regardless of age. The males were more critical of the website and were less satisfied because they wanted more interaction.

The second theme was that good mentors were considered good listeners, relatable, and shared information honestly. The older participants expressed that a mentor should be a good listener and that a mentor should share information honestly, while none of the younger mentees expressed these qualities. The only quality that some of the younger mentees expressed similar to the older mentees was relatability. There was more variability in the younger mentees compared to the older participants when asked what makes a good mentor.

Another theme was the peer-mentoring program for individuals impacted by CKD can provide support. 16 mentees found the program to be supportive, 9 mentees found the program impacted their quality of life, 8 mentees did not answer the questions at the focus groups were appreciative of the mentorship, and 2 mentees that attended the focus groups completed the mentor trainings.

4.2 Outcomes

There have been two studies done in collaboration with the National Kidney Foundation of Michigan, a non-profit similar to the KFCP.^{20,21} They implemented their program of trained mentors to communicate with patients for support. These two studies discussed the possibility and results of the implementation of the website, *kTalk*.^{20,21} One study focused on the development of

this website for young patients with CKD.²¹ The investigators gathered thoughts about the peer-mentoring website with participants younger than our mentees through interviews. Their participants encouraged the development of a CKD support-based website similar to our younger sample size.²¹ The participants stressed that they wanted to communicate with peers close to their age, were disappointed in their inability to remain in communication with them, or did not like how they lived a distance away as some examples.²¹ Although these issues were not brought up significantly in our focus groups, only a couple mentees complained about remaining in touch, some similar apprehensions were voiced in our mentor focus groups. Some mentors were concerned about the challenges of maintaining communication with mentees.

The other study showed to be successful with patient participation since only six younger mentees in our study joined our focus groups. They gathered more participants than our study with 15 out of 38 young adults that used the site or made an account.²⁰ They suggested that other programs, perhaps not online, may compliment an online intervention for these participants.²⁰ Our conclusion was similar since the majority of individuals enrolled in our study ultimately preferred face-to-face interaction. There were suggestions in our focus groups that with the online platform come the opportunity to meet their mentor in-person at least once before online partnership takes place. Like their study, many of our younger participants appreciated the idea of peer-mentorship online.²⁰ We will also investigate the number of people in the study overall that made an account with the website. Over half of their participants did not participate on the website, and some participants explained that they joined the website when they did not use the website.²⁰ When it came to the younger mentees in our study's online intervention, one patient expressed he did not use the CKD peer-mentoring website to communicate with his mentor as much as intended due to its format and suggested it be made into an application.

4.2 Study Strengths and Limitations

Although we had a guide for the focus group discussions, not all questions were asked for every focus group meeting because we invited free discussion. We wanted the group interaction and setting to drive the discussion for each meeting. Consequently, some specific answers were not obtained; however, each facilitator ended the meetings when they felt the appropriate results were gathered. This was also a strength of our study because we were able to gather some proper results without facilitation. A limitation of our study was the variability with mentor participation. For example, we asked the mentors matched with mentees online to reply once a week. Although the mentors were asked to communicate with each of their mentees a number of times per week or month, some did not follow through with the intervention requirements fully. Each mentor approached the partnership after the training differently. The last limitation was that we did not ask the patients what they understood as quality of life. We asked if the mentorship program impacted their quality of life during the focus group discussions, but their quality of life definition may vary from our scientific definition and should be explored in the future.

Chapter 5 Conclusions

Our qualitative study expanded the results of our quantitative results. Instead of solely providing standard assessment results from the peer-mentorship intervention, we were able to delve in the organization of peer-mentorship and what could make peer-mentorship more effective for those impacted by CKD or ESRD in the future with our qualitative data. We recommend that online peer-mentoring programs incorporate a first meeting opportunity for mentees and mentors. We suggest the patients and caregivers supported by mentors have a clear understanding of mentor limitations since participants may have higher expectations than the physical and mental capabilities of the mentors. Our mentors did not mention burnout and wanted even more interaction with their mentees, but it may be best to investigate the possibility of mentor burnout in addition to patient and caregiver support based on our mentee focus group results.

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Appendix

Textbox and Tables

Textbox 1. Focus Group Guide for Mentees

Before we start, do you have any questions?
(answer as appropriate)

1. Let's start off by getting to know each other and about some of our past experiences. Could you tell us your first name and a little about yourself?

Overview of the Program:

2. We'd like to hear your feedback about the mentorship program.

PROMPTS:

What were the positive aspects of the program?
What could have been done differently?

3. Has the mentorship experience been what you expected? Why or why not?

Mentor/Mentee Experiences:

In this study, we are trying to understand the role of mentors in impacting mentees' through their chronic kidney disease.

4. Describe your feeling in anticipation of the visits with your mentor.
5. Does your mentor share his/her personal experiences?

PROMPTS:

If so, how frequently? In what way?
How has this impacted you?

6. What are some qualities of a "good mentor"?
7. How well was your mentor prepared for the mentorship? What did he/she do very well? What could he/she have done differently?
8. Did your mentor appear committed to the mentorship?
9. Do you consider your mentor a part of your support structure?
10. Has the mentorship helped you be more involved in your own care?
11. How has the mentorship impacted your quality of life?

12. What can the program do to make the mentor/mentee relationship stronger and more effective?
13. When questions about medical care came up, how often did your mentor provide medical advice? Refer you to your medical team?
14. We wanted you to help us think about this mentorship program. Is there anything we missed? Is there anything that you want to say that you didn't get a chance to say?

Table 3-1. Demographic Characteristics

Focus Group Mentees	N=34
Sex	
Female	13 (38.24)
Male	21 (61.76)
Race	
Black or African American	20 (62.50)
White	12 (37.50)
Hispanic, Latino, or Spanish descent	2 (5.88)
Not Hispanic, Latino, or Spanish descent	32 (94.12)
Age	
Mean	52.765
Std Dev	13.326
Median	52.5

Table 3-2. Participant Modalities

Patient and Caregiver Status		
Patient	32	94.12
Caregiver	2	5.88
Modality and Mentee Status		
Hemodialysis	27	79.41
Peritoneal dialysis	4	11.76
Home hemodialysis	1	2.94
Caregiver to Hemodialysis	1	2.94
Caregiver to Peritoneal dialysis	1	2.94
Intervention		
Face-to-face Partnership	20	58.82
Online Partnership	14	41.18