The Most Important Thing We Can Do Is Listen: Making Peer Mentoring Available for All

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The purpose of this research was to increase the availability of mentor training materials for people with kidney disease, learning disabilities, and vision difficulties through the creation of an audiobook and a large font textbook to improve their participation in the training process. A qualitative approach was utilized to evaluate the participants' training experience. A secondary goal of this project was to assess the mentee's quality of life (QOL) prior to being matched with a mentor and then 3–6 months after the match. During our yearlong study, 11 participants completed the peer mentor training classes and 5 mentees were matched with the mentors. Mentee QOL was measured by the CDC's Healthy Days Measure before participating in the peer mentoring program and reflected variable QOL for mentee participants. Findings indicate that participants utilized the audiobook and felt it aided their training experience.

INTRODUCTION

The Kidney Foundation of Central Pennsylvania (KFCP), in Harrisburg, PA, has a peer mentoring program, The Patient and Family Partner Program (PFPP). Since its inception in 2004, the PFPP has given people affected by kidney disease opportunities to mentor others going through similar experiences. The pioneer behind the PFPP, Peggy Jayne Pierce, identified the need to connect with someone who "has been there." Peggy was a registered nurse and a patient with chronic kidney disease (CKD). She wanted to move beyond statistics and textbooks, and towards lessening anxieties and increasing knowledge about kidney disease. Peggy recognized this alternate way of coping and, with the help of various renal professionals, developed the PFPP curriculum, now known as the *Certified-Partner Candidate Handbook*.

Nationally, peer mentoring programs continue to grow to support people affected by kidney disease and are effective in improving quality of life (QOL) and reducing caregiver burden (Ghahramani, 2019). Peer mentoring is known to enhance the health and well-being of individuals and families affected by kidney disease. Peer-led mentoring is an effective strategy in patient education for those considering various treatment methods (Ghahramani, 2015). Peer mentors may also encourage patient engagement.

Current research suggests that patients with chronic illnesses, such as kidney disease, can also have depressive symptoms, significantly higher than the general population (Nelson et al., 2003). Depressive symptoms can also lead to worsened quality of life, impair recovery, result in poor treatment adherence, and worsen mental health status (Saravanan, 2009). Living with a chronic illness can be isolating. The effectiveness of peer mentoring may be attributed to the notion of relating and shared experiences.

The purpose of the PFPP is to provide a valuable resource to those affected by kidney disease and begins with the training of mentors. The mentors are people with kidney disease or family members of people with kidney disease who have learned to live well with their disease and want to help others. The participants attend weekly two-hour classes for six weeks. Traditionally, these classes are led by the PFPP coordinator and are face-to-face using the *Certified-Partner Candidate Handbook*. Participants have required readings and homework each week. During the classes, a PFPP trainer reviews the chapter materials with attendees via a PowerPoint presentation. These trainers are volunteers from the community with kidney disease experience.

It is imperative that the PFPP be available to all and our goal in this project was to increase the availability of the training classes through the creation of an audiobook and a large font textbook to be used by peer mentors with reading or vision issues. Like many states, Pennsylvania has a growing number of patients with a CKD diagnosis. The most common cause of kidney failure is diabetes. A common complication of diabetes is diabetic retinopathy, a condition that affects eyesight and may lead to difficulties with vision. According to the Centers for Disease Control and Prevention (CDC, 2019), approximately 3% of Pennsylvania and almost 5% of the United States populations have received a diagnosis

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of blindness or have serious difficulty seeing. In addition, 4.6 million Americans report having a learning disability (Cortiella & Horowitz, 2014). The secondary aim of this study was to assess mentee's quality of life (QOL) prior to participating in the peer mentor program to describe baseline mentees' QOL, measure change, and inform other peer mentor programs.

This work was inspired by R.R., a patient with kidney failure receiving in-center hemodialysis. She struggled with our training materials and was frustrated with the learning process. On multiple occasions, she even considered not completing the training. She was unsure if she should share her diagnosis of dyslexia with the PFPP coordinator and volunteer trainers. R.R. shared that when she was growing up, many did not have knowledge about learning disabilities. She struggled with learning and did not complete high school. Life experience had taught her to be an advocate for herself.

R.R. took a risk and shared her frustrations and her diagnosis of dyslexia with her dialysis social worker. She was encouraged when her social worker assisted her with the reading materials and the homework for the PFPP. Due to this positive experience, she was willing to share her story with others in the mentor training class. This encouraged others to express barriers in completing the coursework, such as blindness and sight issues. R.R. felt that her anger and frustration with dyslexia were relieved by sharing her story. R.R. completed the mentor training class and felt that being a mentor was like being in a "mini-support group" for persons with kidney disease. R.R. and others inspired a reevaluation of our training materials.

METHOD

Following modifications to the overall administration of the program due to the COVID-19 pandemic, two mentor training classes were held virtually in 2020, using the new training materials. Eligibility criteria for this study were peer mentor trainees who were: 1) patients or caregivers living with kidney disease, preferably stages 4–5 CKD; 2) adults over age 18; and 3) residents of Central Pennsylvania (the coverage area for the KFCP).

After the conversion of the *Certified-Partner Candidate Handbook* to an audiobook, an evaluation was conducted. The goals were to: a) assess if the audiobook increased the number of peer mentor trainees who have visual or learning disabilities and improved their participation in the training process; and b) assess QOL of mentees. QOL was measured by the Healthy Days Measure which is used by the CDC (2018). The study was approved by the Kidney Foundation of Central PA Board. Written consent was obtained by each participant.

As stated, due to COVID-19, the mentor training classes were held virtually. The classes were facilitated by the PFPP coordinator and were held one evening per week over six weeks. Volunteer trainers remained and provided the weekly presentations and goals of the program, despite the transition from face-to-face classes to virtual classes. Upon completion of the class, participants completed a questionnaire to collect their thoughts and opinions regarding the updated training materials and the impact on their learning. Upon successful completion, each mentor was attempted to be matched with a mentee. For those who were able to be matched, the mentees were provided with the Healthy Days Measure for baseline QOL prior to matching and 3–6 months later.

RESULTS

From January 1 to December 31, 2020, 11 participants received the mentor training, consisting of two mentor training classes, held virtually. The audiobook was given to each participant in addition to the printed mentor training manual and other class materials. The response rate for the post-assessment questionnaire was 100%. Two participants did not complete all the coursework for training. One declined to do the homework assignments and one was unable to attend all the classes due to health issues and hospitalizations during the training period. Both were offered opportunities to complete the coursework.

Demographic characteristics of the trainees are highlighted in **Table 1**. Participants included seven men and four women ranging in age from 30 to 74 years. Six participants were receiving in-center hemodialysis, two participants were receiving peritoneal dialysis, one participant was on home hemodialysis, one participant was a kidney transplant donor and one was a caregiver. Two of the participants had a history of receiving a kidney transplant.

Of the participants, five self-reported visual difficulties, including diabetic retinopathy, cataracts, partial and complete blindness, glaucoma, and nearsightedness. Three participants also reported they wore eyeglasses and one trainee used reading glasses to read small print. Two participants self-reported attention deficit hyperactivity disorder (ADHD) as a learning disability, while one participant reported visual perceptual and visual motor deficits. Educational levels were also reported: three had graduated high school or obtained a general educational development (GED), two reported "some college," four had college degrees and one had a graduate degree.

The self-reported use of the audiobook is highlighted in **Figure 1**. Of the participants, five used the audiobook during the mentor training. Three participants listened 1–2 times per week, while two participants listened to the materials

3–5 times per week. All participants felt the audiobook improved their training experience and one of these participants reported the audiobook was "well done." Five of the participants who didn't use the audiobook reported that they preferred reading the printed mentor training manual. One participant didn't use the audiobook due to "forgetting about it," and suggested that the program coordinator remind participants of the materials during the training period.

Five mentees were matched with the participants who completed the mentor training classes during our research period. Demographic characteristics of the mentees are highlighted in **Table 2**. Each of the mentees was asked to complete the Healthy Days Measure (see **Figure 2** for questionnaire) with the PFPP program coordinator prior to being matched with their mentor. For *question 1*, no mentees reported excellent, very good or good health. For those who completed the measure, one reported fair health, one reported poor health, and two reported fair/poor health. For *question 2*, one reported 2 days in a 30-day period that physical health was not good, one reported 5 days, one reported 20 days, and two reported 30 days. For *question 3,* one reported 0 days in a 30-day period that mental health was not good, one reported 1 day, one reported 28 days, and two reported 30 days. For *question 4*, one reported 0 days in a 30-day period where their physical or mental health kept them from doing their usual activities, two reported 20 days, one reported 25 days, and one reported 28 days. Additional data points about mentee quality of life will be assessed in the future to compare these findings before and after participating in the peer mentor program.

DISCUSSION

People who experience a chronic disease, like chronic kidney disease, have many stressors. A peer mentoring program is a valuable tool for people who are doing well with their disease to help others who may be struggling. Mentors who have participated in this program in the past have shared how helpful the education from the mentor classes has been with managing their own disease and lives. There have been people who have requested to participate in the classes, but did not enroll due to sight issues or learning disabilities. Providing an adequate learning environment for those with learning disabilities or visual difficulties is integral to the program's success. This research study was motivated by a participant who shared her struggles with dyslexia and her concern that she could not complete the homework without assistance. Further exploration into other vulnerable populations' possible participation in this program may result in increased healthcare engagement, as well as autonomy in healthcare decisions.

One limitation of this study was the small sample size, due to the restructuring of the mentor training classes due to COVID-19. Because of COVID-19, an online platform was created and there were delays with starting the first training class. Another limitation was that participants needed access to the internet and needed to be familiar with Zoom or willing to download and learn this software platform. Kidney disease care providers who made referrals to the program also had to be educated about the new processes and requirements. Prior to COVID-19, mentors would typically meet face-to-face with their mentees. During the research period, the mentors were encouraged to use phone calls, texts, or emails for their meetings with mentees. This may have also limited participants' interest in the mentor training classes. During the first class, 5 participants did not use the audiobook and one participant during the first class suggested the PFPP program coordinator provide reminders to use the audiobook during the training period and this was implemented during the second training period. The lack of reminders could have contributed to lessened use of the audiobook during the first training class.

The large font textbook was not used during mentor training classes due to delays in the editing process. Because of this, the research team was unable to assess participants' thoughts or opinions on it. The reformatted textbook has since been completed and will be offered to all participants with sight issues in upcoming mentor training classes.

Despite these limitations, we are encouraged by the results and promise of this study. As an innovative approach to aiding those who live with CKD, peer mentoring may increase both caregiver and patient quality of life. Offering these services to those who have vision or learning difficulties broadens the potential audience. Peer mentoring could be translated for other chronic health conditions and lessen patient anxiety. Mentors encourage and empower those in similar situations through the strength of shared experiences.

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Table 1. Characteristics of the peer mentor trainees

	Number of participants (n = 11)
Gender	
Male	7
Female	4
Age	
30–40	3
40–50	2
50–60	2
60–70	3
70–80	1
Visual Difficulties	
Cataracts	4
Diabetic retinopathy	3
Glaucoma	1
Partial or complete blindness	1
No vision difficulties	2
Learning Disabilities	
ADHD	2
Visual perceptual and visual motor deficit	1
No learning disabilities	8

Table 2. Characteristics of the peer mentor mentees

	Number of mentees (n = 5)
Gender	
Male	4
Female	1
Age	
30–40	0
40–50	1
50–60	1
60–70	2
70–80	1
Ethnicity	
White, non-Hispanic	4
African American	1
Educational Level	
High school	4
Bachelor degree	1
Master's degree	0

Figure 1. Peer mentor trainee self-reported use of the training audiobook (n = 11)

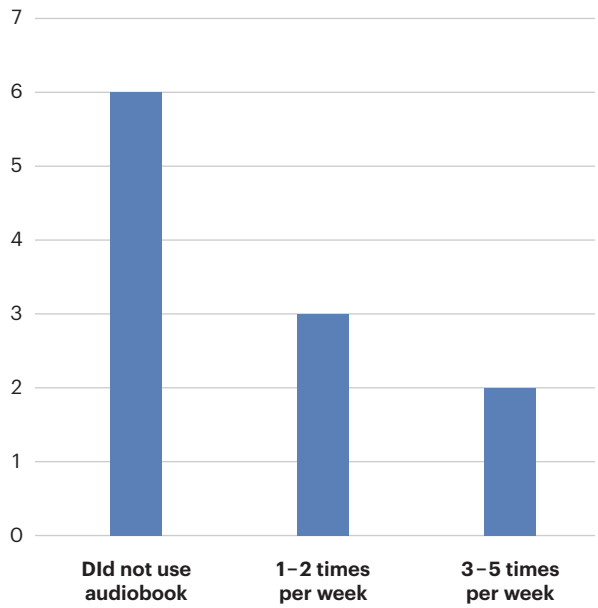

Figure 2. Healthy Days Measure Questions (Centers for Disease Control and Prevention (CDC), 2018).

1. Would you say that in general your health is excellent, very good, good, fair, or poor?
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

Source: Centers for Disease Control and Prevention (CDC). (2018 October 31). Health-Related Quality of Life (HRQOL); Methods and measures. CDC website. Available at: https://www.cdc.gov/hrqol/methods.htm

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