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Baker, Alexandra M., "Peer Mentoring to Enhance Parent Coping with Child's New Chronic Kidney Disease Diagnosis" (2021). *Nursing Graduate Publications and Presentations*. 48.
https://pilotscholars.up.edu/nrs_gradpubs/48

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Peer Mentoring to Enhance Parent Coping with Child's New Chronic Kidney Disease

Diagnosis

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Author Note

The author has no known conflicts of interest to disclose.

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Abstract

Pediatric kidney disease diagnoses are stressful for the entire family and many parents lack social outlets that understand the associated lifestyle changes and stressors. There is a variety of evidence in the literature supporting the use of peer mentoring to promote positive coping among patients with chronic disease and their family members. This paper describes the development and implementation of a peer mentoring program among parents of children newly diagnosed with kidney disease to determine the impact on parent coping with their child's diagnosis, as assessed through the Coping Health Inventory for Parents (CHIP-16). Results are discussed, as well as lessons learned and recommendations that may guide future peer mentoring programs among this population.

Keywords: peer mentoring, parent mentoring, positive coping, pediatric kidney disease, new diagnosis, new kidney disease diagnosis

Peer Mentoring to Enhance Parent Coping with Child's New Chronic Kidney Disease

Diagnosis

Affecting approximately 31.3 children per million in the United States and 20 children on average in the Pacific Northwest each year, chronic kidney disease (CKD) and end-stage renal disease (ESRD) are complex medical conditions that greatly impact both patients and their families (Centers for Disease Control and Prevention [CDC], n.d.; Jill Brown, personal communication, October 27, 2020).

Upon diagnosis, patients and families become immersed in a new reality, consisting of complex medication regimens, frequent hospitalizations, missed school days, tedious in-home and in-clinic treatments, lifelong lifestyle changes, and decreased survival (CDC, n.d.; United States Renal Data System, 2020). Attempting to balance the care of a chronically ill child with other responsibilities such as work, family, finances, and social life, many parents experience excessive fatigue and emotional distress (Geense et al., 2017). Over time, stress and inadequate support results in low parent quality of life and poor parent mental health, adversely impacting child health outcomes, potentiating this vicious cycle (Bradshaw et al., 2019; Collins et al., 2020; Geense et al., 2017).

Charged with supporting these individuals, Northwest Kidney Kids (NWKK) serves youth from birth to age eighteen with CKD and ESRD and their families in the Pacific Northwest, aiming to “empower kidney kids to take charge of their health, embrace their future, and achieve lifelong success” (Northwest Kidney Kids [NWKK], 2020a). Northwest Kidney Kids facilitates a variety of programs to support kidney kids and their families, but no programming exists to support parents of children newly diagnosed with kidney disease (Jill Brown, personal communication, October 27, 2020; NWKK, 2020b). This gap in organizational

programming provides an excellent opportunity to better support parents of children newly diagnosed with CKD or ESRD.

Available Knowledge

Robust evidence in the literature supports the efficacy of peer support in promoting positive coping for individuals and families with chronic disease (Channon et al., 2016; Chopoglou et al., 2019; Dunn et al., 1999; Moody et al., 2019; Paloma et al., 2020; Ramfelt et al., 2020; Rearick et al., 2017; St. Clair Russell et al., 2017; Sullivan-Bolyai et al., 2010; Tully et al., 2017; Williams et al., 2018). Several studies evaluating peer mentoring among patients and families with chronic disease demonstrate that peer mentors share experiences and knowledge that providers cannot (Channon et al., 2016; St. Clair Russell et al., 2017). In a variety of programs, the greatest benefit of peer mentoring for mentees is shared experiences and associated understanding from mentors (Chopoglou et al., 2019; Dunn et al., 1999; Ramfelt et al., 2020; & Rearick et al., 2011). Individuals in peer mentoring programs are also more likely to use positive coping mechanisms than the control, demonstrating that peer mentoring programs help promote positive coping behaviors (Chopoglou et al., 2019). These findings in the literature suggest that a peer mentor program would enhance coping when applied to parents of children with newly diagnosed kidney disease.

Rationale

Lazarus and Folkman's Psychological Stress and Coping Theory underpins the parent mentoring program. According to Lazarus and Folkman (1984), when individuals appraise situations as stressful, they look to their environment for available coping strategies (Biggs et al., 2017; Lazarus & Folkman, 1984). Depending on available coping resources, individuals enact problem-oriented coping, directly working to "manage the stressor," emotion-oriented

coping, regulating stressor-induced emotions, or meaning-focused coping, realizing a positive meaning in the stressor (Biggs et al., 2017). Emotion-oriented coping can be successful as a short-term response to a stressor but produces negative outcomes for the individual if used long-term, while problem-oriented and meaning-focused coping produce positive long-term outcomes (Biggs et al., 2017). The parent mentoring program provides the mentee with additional support and resources, helping facilitate problem-oriented or meaning-focused coping.

Aims

The intervention pairs new and experienced parents with overarching aims to facilitate sharing, establish a supportive relationship, and promote positive coping with child's new CKD/ESRD diagnosis.

Methods

Intervention(s)

The project coordinator obtained University of Portland Internal Review Board approval prior to implementation. Implementation began with mentor and mentee recruitment through social media and referral from NWKK staff and nephrology professionals in the Pacific Northwest, following specific inclusion criteria, as outlined in Appendix A. All participants completed a consent to participate, describing risks and benefits of participation, and a demographics questionnaire (modified from the evidence-based Sociodemographic Variables Questionnaire, available in appendix B) that was used to pair mentors and mentees according to an algorithm (available in appendix C) (Toledano-Toledano et al., 2019). Mentees completed a pre-intervention CHIP-16 questionnaire, a valid and reliable, evidence-based tool to evaluate coping among parents of children with chronic disease (Toledano-Toledano et al., 2020). All

mentors participated in a virtual training session, discussing program components, therapeutic communication, active listening, boundary setting, and more as outlined in a mentor training manual (available upon request from the author).

The mentoring relationship began with a phone or video call or in-person meeting, as arranged by the mentor and mentee, followed by weekly correspondence through means determined by the mentoring pair. The mentoring relationship lasted for eight weeks, discussing topics the mentee desired. The project coordinator checked in with mentors via email every two to three weeks throughout the intervention to solicit feedback in real-time. At the end of eight weeks, mentors and mentees completed a post-intervention evaluation questionnaire (available in appendix E), developed in cooperation with NWKK stakeholders, and mentees completed another CHIP-16 questionnaire. All questionnaires were administered online through the secure Qualtrics survey platform.

Measures

The following outcome and process measures guided program evaluation:

Outcome measures include:

1. Newly diagnosed parents will demonstrate a significant increase in coping behaviors used on post-intervention CHIP-16 questionnaire at the conclusion of the eight-week mentoring program.
2. Newly diagnosed parents will rate CHIP-16 coping behaviors 10, 12, and 13 as significantly more helpful upon conclusion of the eight-week mentoring program.
3. Newly diagnosed parents will rate mentor helpfulness in coping with their child's diagnosis at least 7 or higher on a 10-item Likert scale measurement upon conclusion of the eight-week mentoring program.

Process measures include:

1. Mentors and mentees will communicate at least one time per week for the duration of the eight-week mentoring program.
2. Mentors will rate mentor training helpfulness at 7 or higher on a 10-item Likert scale measurement at the conclusion of the eight-week mentoring program.

Analysis

The project coordinator analyzed quantitative data using descriptive statistics to determine correlations and significance among data. The project coordinator also analyzed qualitative data for themes among participant responses.

Results

The peer mentoring program yielded both statistically and clinically significant results. There was a significant difference between pre and post intervention CHIP-16 scores overall, with significantly higher scores overall across questionnaire domains post-intervention as demonstrated through a two tailed t- test ($p = 0.002$). This meets the first program outcome measure, as there was a significant difference between pre and post intervention CHIP-16 data. There was no significant difference in pre- and post- CHIP-16 item 10 ($p = 0.4$), 12 ($p = 0.1$), and 13 ($p = 0.4$) helpfulness via a two tailed t-test. With that said, mentees rated items 10, 12, and 13 as more helpful post intervention when compared to pre-intervention helpfulness, though the difference was not significant. This means that outcome measure 2 was somewhat met, as there was an improvement in pre and post intervention CHIP-16 item 10, 12, and 13 helpfulness. Outcome measure 3 was met, as mentees rated mentor helpfulness in coping with their child's diagnosis at 9 on a 10 item Likert scale measurement (ranging from *not helpful at all* to *extremely helpful*), which exceeds the program goal of 7 out of 10.

Mentors related that they communicated, on average, less than one time per week, which does not satisfy process measure 1, as mentors and mentees did not communicate on a weekly basis. Seventy-five percent of mentors stated they communicated with their mentee less than once per week, while 25% said they communicated weekly. With that said, a variety of qualitative data revealed that the program was still helpful despite the less frequent communication, which was tailored to the busy schedules of both mentors and mentees. For example, mentees rated program helpfulness at 8.25 and program helpfulness in understanding child's diagnosis at 9 on a 10-item Likert scale. Finally, mentors rated mentor training at 7.25 on a 10-item Likert scale ranging from *not helpful at all* to *extremely helpful*, satisfying process measure 2, as training helpfulness was rated greater than 7.

Discussion

The parent mentoring program demonstrates that peer mentoring enhances parent coping with their child's new kidney disease diagnosis. Program outcome measures 1 and 3 were met and process measure 2 was met. While not all outcome and process measures were met, there was a variety of clinically significant data that supports the use of peer mentoring among parents of children newly diagnosed with kidney disease.

Program findings fit amongst evidence in the literature, as peer mentoring enhances coping and increases support for individuals with chronic disease and their families (Channon et al., 2016; Chopoglou et al., 2019; Dunn et al., 1999; Moody et al., 2019; Paloma et al., 2020; Ramfelt et al., 2020; Rearick et al., 2017; St. Clair Russell et al., 2017; Sullivan-Bolyai et al., 2010; Tully et al., 2017; Williams et al., 2018). Just as mentees in the parent mentoring program reflected that it was helpful to talk to someone who knew what they were going through, peer mentoring program participants in the literature stated that the most significant contribution to

overall program helpfulness was being able to talk to someone with similar medical experiences ($p < .001$) (Chopoghlou et al., 2019; Dunn et al., 1999). Perhaps the frequency of communication is not essential, but rather the ability to share experiences and receive support as needed is the key to program success, as mentors and mentees in the peer mentoring program did not communicate on a weekly basis as initially required. Despite 75% of mentor-mentee pairs communicating less than one time per week, all mentees rated “having someone who understood what I was going through” as one of the most helpful parts of the mentoring program, and 50% of mentees rated “having someone to talk to who was not part of my family or friends” as one of the most helpful parts of the mentoring program. Furthermore, 100% of mentors rated their likelihood to mentor again at 10 on a 0 to 10 Likert scale, 0 being not likely at all and 10 being extremely likely. This demonstrates that peer mentoring is not only valuable for the mentee, but also the mentor.

The parent mentoring program was primarily limited by geography. Half of mentees related that they would like a mentor closer to their location, as many mentees were not from the Pacific Northwest, while all mentors lived in Oregon and Washington. With that said, all mentors reflected that they communicated with their mentee by digital means. In the future, it would be interesting to see if mentors and mentees who live in the same geographic region would meet in person or continue to communicate digitally. Additionally, perhaps future mentor recruitment could occur at various pediatric nephrology centers throughout the United States, rather than just in the Pacific Northwest.

Implementation Facilitators

Multiple implementation facilitators and strategies promote program sustainability. First, the parents mentoring program fulfills an organizational need, as NWKK lacks programming for

newly diagnosed parents. The program supports the organizational mission and vision to support children with kidney disease, another incentive for the organization to sustain it (NWKK, 2020). The project coordinator also consulted stakeholders throughout program development to ensure that organizational needs were met.

Implementation Barriers

Several implementation barriers exist that may threaten program sustainability. First, the organization has limited staff, making it difficult to find staff available to continue program implementation after the project concludes. To negate this barrier, the project coordinator communicated with the NWKK executive director regarding hours needed to implement the parent mentoring program so NWKK can anticipate future needs and hire additional staff if necessary. Second, a lack of newly diagnosed parents may threaten program sustainability, as no parents would be available for mentoring. To manage this barrier, NWKK plans to have a group of trained mentors ready to serve as new families are diagnosed, allowing the mentoring program to occur on a rolling basis, instead of several cohorts per year. Third, trained mentors may become too busy with their own child and commitments to serve as mentors regularly. To avoid this barrier, NWKK will train a large mentor pool to account for lost mentors and large mentee influx. While there are several potential barriers to program sustainability, barrier management plans are in place to promote program sustainability and success.

Conclusion

A pediatric kidney disease diagnosis imposes stress upon parents, negatively impacting mental health. As demonstrated through the newly diagnosed parent mentoring program, peer mentoring programs are a realistic, effective solution to promote coping with a child's new kidney disease diagnosis.

References

- Biggs, A., Brough, P., & Drummond, S. (2017). Lazarus and Folkman's psychological stress and coping theory. In Cooper, C., & Quick, J. (Eds.), *The Handbook of Stress and Health: A Guide to Research and Practice* (pp.351-364). Wiley Blackwell.
- Bradshaw, S., Bem, D., Shaw, K., Taylor, B., Chiswell, C., Salama, M., Bassett, E., Kaur, G., & Cummins, C. (2019). Improving health, wellbeing and parenting skills in parents of children with special health care needs and medical complexity - a scoping review. *BMC pediatrics*, 19(1), 301. Doi: 10.1186/s12887-019-1648-7
- Centers for Disease Control and Prevention. (n.d.). Chronic Kidney Disease Surveillance System. Retrieved from <https://nccd.cdc.gov/ckd/detail.aspx?QNum=Q243#refreshPosition>
- Channon, S., Lowes, L., Gregory, J., Grey, L., & Sullivan-Bolyai, S. (2016). Feasibility of parent-to-parent support in recently diagnosed childhood diabetes. *The Diabetes Educator*, 42(4), 462-469. doi: 10.1177/0145721716644673
- Chopoghlu, S., Hanifi, N., & Varjoshani, N. (2019). A comparative study of uncertainty and coping strategies of patients with multiple sclerosis for members and nonmembers in peer groups. *Health Care for Women International*, 43(3), 354-367. doi: 10.1080/073993322.2019.1621317
- Collins, A., Burchell, J., Remedios, C., & Thomas, K. (2020). Describing the psychosocial profile and unmet support needs of parents caring for a child with a life-limiting condition: A cross-sectional study of caregiver-reported outcomes. *Palliative Medicine*, 34(3). Doi: 10.1177/0269216319892825
- Geense, W. W., Gaal, B. G. I., Knoll, J. L., Cornelissen, E. A. M., & Achterberg, T. (2017). The

- support needs of parents having a child with a chronic kidney disease: a focus group study. *Child: Care, Health & Development*, 43(6), 831–838. Doi: 10.1111/cch.12476
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.
- Northwest Kidney Kids. (2020a). About Us. Retrieved from <https://www.nwkidneykids.org/p/Kidney-Transplant-Patient-Portland-OR-About-Us-p122.asp>
- Northwest Kidney Kids. (2020b). Programs. Retrieved from <https://www.nwkidneykids.org/p/Kidney-Transplant-Patient-Portland-OR-Programs-p123.asp>
- Paloma, V., Morena, I., Sladkova, J., Lopez-Torres, C. (2020). A peer support and peer mentoring approach to enhancing resilience and empowerment among refugees settled in southern Spain. *Journal of Community Psychology*, 2020(48), 1438-1451. doi: 10.1002/jcop.22338
- St. Clair Russell, J., Southerland, S., Huff, E., Thomson, M., Meyer, K., & Lynch, J. (2017). A peer-to-peer mentoring program for in-center hemodialysis: A patient-centered quality improvement program. *Nephrology Nursing Journal*, 44(6), 481-496.
- Toledano-Toledano, F., Moral de la Rubia, J., McCubbin, L., Cauley, B., & Luna, D. (2020). Brief version of the coping health inventory for parents (CHIP) among family caregivers of children with chronic diseases. *Health and Quality Life Outcomes*, 18(104). doi: 10.1186/s12955-020-01357-S
- Toledano-Toledano, F., Rodriguez-Rey, R., Moral de la Rubia, J., & Luna, D. (2019). A sociodemographic variables questionnaire for research on family caregivers of children with chronic disease. *BMC Psychology*, 7(85). Doi: 10.1186/s40359-019-0350-8

United States Renal Data System. (2020). USRDS Annual Data Report. Retrieved from <https://adr.usrds.org/2020>

Appendix A

Inclusion Criteria for Program Participation

Mentors

- Child diagnosed with CKD stage 4 or 5 two or more years ago
- Compliant with child's treatment regimen, as determined by NWKK staff or nephrology professionals.
- Identified as an appropriate mentor by NWKK staff or nephrology professionals
- English or Spanish speaking
- Literate
- No hearing/visual/vocal impairments
- Possesses a working phone and internet access

Mentees

- Child diagnosed with CKD stage 3 or later in the past 6 months
- English or Spanish speaking
- Possesses a working phone

Appendix B

Demographics Questionnaire

Demographics Questionnaire*

Parent/Guardian Name(s): _____

Date: _____

1. What is *your* age? _____
2. *Your* sex:
 - a. Male
 - b. Female
 - c. Other
3. What is the diagnosis of *your child*? (please list diagnosis): _____
 Select *your child's* stage of Chronic Kidney Disease (CKD) or end-stage renal disease (ESRD):
 - a. CKD 3
 - b. CKD 4
 - c. ESRD/CKD 5
 - d. On dialysis
 - i. Peritoneal dialysis (PD)
 - ii. Hemodialysis (HD)
4. *Child's* sex:
 - a. Male
 - b. Female
 - c. Other
5. *Child's* current age: _____
6. *Child's* age when diagnosed: _____
7. *Your* marital status:
 - a. Married
 - b. Living together but not married
 - c. Separated
 - d. Divorced
 - e. Single parent
 - f. Widow
 - g. Other: _____
8. What is your relationship to the child?
 - a. Mother
 - b. Father

c. Grandparent

d. Other: _____

9. How long ago was your *child* diagnosed?

a. A few weeks ago

b. 3 months ago

c. 6 months ago

d. 1 year ago

e. 3 years ago

f. 5 years ago

g. 10 years ago

h. Other: _____

10. From where do *you* primarily receive support? (select all that apply)

a. Family

b. Friends

c. Business

d. Religion

e. Government

f. Hospital/clinic

g. I don't receive support

h. I don't receive enough support

*Adapted from the Sociodemographic Variables Questionnaire (Q-SV) for Research on Family Caregivers of Children with Chronic Disease, Retrieved from: Toledano-Toledano, F., Rodriguez-Rey, R., Rubia, J., & Luna, D. (2019). A sociodemographic variables questionnaire (Q-SV) for research on family caregivers of children with chronic disease. *BMC Psychology*, 7(85). doi: 10.1186/s40359-019-0350-8

Appendix C

Mentor-Mentee Pairing Algorithm

Parent Peer Mentoring Program: Mentor – Mentee Pairing Criteria						
<i>Mentors and mentees will be paired based on the following criteria:</i>						
High priority	1. Diagnosis: CKD 3		CKD 4	CKD 5/ESRD Dialysis method: PD or HD		
	2. Language: Language spoken at home			Fluent language(s)		
Priority ↓	3. Child Age:		Pre-K	Elementary	Middle School	
	Infant <1 year	2-4	5-10	11-13	High School 14+	
	4. Geographic Region:		Central OR + Southern OR	Eastern OR + Eastern WA + ID	Northern WA + Central WA + AK	
	Northwest OR + Southwest WA					
Low priority	5. Parent Relation and/or Gender:			Single Male vs. Female		
	Married					
6. Personality Factors: To be determined by Northwest Kidney Kids staff						

Appendix D

Coping Health Inventory for Parents (CHIP-16)

Coping Health Inventory for Parents (CHIP)-16 Date: _____

For each coping behavior listed, please check the box indicating how helpful the behavior is to you. If you do not use the coping behavior, please check the box indicating why you did not use it.

Coping Behavior	Used coping behavior				Did not use coping behavior	
	Extremely helpful	Moderately helpful	Minimally helpful	Not helpful	Chose not to use	Not possible
1. Believing my child will get better.						
2. Investing myself in my children.						
3. Telling myself that I have many things I should be thankful for.						
4. Showing that I am strong.						
5. Getting other members of the family to help with chores and tasks at home.						
6. Having my child with the medical condition seen at the clinic/hospital on a regular basis.						
7. Believing that the medical center/ hospital has my family's best interest in mind.						
8. Being able to get away from the home care tasks and responsibilities for some relief.						
9. Purchasing gifts for myself and/or family members.						
10. Talking to someone about how I feel.						
11. Going out with my spouse on a regular basis.						
12. Building close relationships with people.						
13. Talking with other parents in the same type of situation and learning about their experiences.						
14. Talking with the medical staff when we visit the medical center.						

Coping Health Inventory for Parents (CHIP)-16 Date: _____

For each coping behavior listed, please check the box indicating how helpful the behavior is to you. If you do not use the coping behavior, please check the box indicating why you did not use it.

Coping Behavior	Used coping behavior				Did not use coping behavior	
	Extremely helpful	Moderately helpful	Minimally helpful	Not helpful	Chose not to use	Not possible
15. Reading more about the medical problem which concerns me.						
16. Being sure prescribed medical treatments for child are carried out at home on a daily basis.						

Appendix E

Post-Intervention Questionnaire

1. What was your role in the parent mentoring program?
 - a. Newly diagnosed parent (mentee)
 - b. Parent Mentor

If participants answered “A” for question 1, they received the following questions:

2. What were the most helpful parts of the mentoring program? (select all that apply)
 - a. Having someone who understood what I was going through
 - b. Having someone to talk to who was not a part of my family or friends
 - c. Having someone who knew about community resources
 - d. Having someone who helped me find the most helpful medical supplier
 - e. Having someone who helped me find new ways to deal with my child’s diagnosis
 - f. Having someone who knew how to prepare food with my child’s diet needs
 - g. Having someone who knew how to get my child to take their meds
 - h. Other (please specify)
 - i. Other (please specify)
3. On a scale of 0-10, how helpful was the mentoring program for you?
4. On a scale of 0-10, how helpful was the mentoring program for you?
5. On a scale from 0-10, how helpful was your mentor in coping or dealing with your child's diagnosis?
6. What did you like best about the mentoring program?
7. What was missing from the mentoring program that would have been helpful?
8. Do you have any other comments about the program you would like us to know?

If participants answered “B” for question 1, they received the following questions:

1. On average, how often did you communicate with your mentee? (including phone call, text message, email, social media, in-person meeting)
 - a. Only one time per week
 - b. 2-3 times per week
 - c. 4-5 times per week
 - d. More than 5 times per week
2. On a scale from 0-10, how helpful was the mentor training in preparing you to be a mentor?
3. What was missing from mentor training that would have been helpful?
4. On a scale from 0-10, how likely are you to be a mentor again?
5. What was the best part of the mentoring program for you?
6. What was missing from the mentoring program that would have been helpful?
7. Is there anything else you think we should know about the mentoring program?