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Advancing Pediatric Hemodialysis Care through the Novel Intervention in Children's Healthcare (NICH) Program

Jessica Williams[1], Natalia Garban[2], Cynthia Wong[1], Elizabeth Talley[1]

[1]Department of Pediatric Nephrology, Lucile Packard Children's Hospital Stanford, Palo Alto, USA
[2]NICH Program Care Team, Lucile Packard Children's Hospital Stanford, Palo Alto, USA
Email: jawilli@stanford.edu, ngarban@stanfordchildrens.org, wongcy8@stanford.edu, etalley@stanford.edu

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Abstract

Racial, ethnic, and socioeconomic disparities present daunting hurdles that prevent equitable health outcomes for patients with end-stage kidney disease (ESKD) on hemodialysis. Additional resources, such as the Novel Intervention in Children's Health (NICH) at Lucile Packard Children's Hospital Stanford, provide individualized support to best assist families by assessing barriers to care with the goal of improving health outcomes. In this retrospective cohort study, we reviewed patients with ESKD on hemodialysis involved in NICH to explore if NICH serves as a liaison between the patients and multidisciplinary medical team and to explore if NICH helps patients better manage the challenges of end-stage kidney disease. Through the electronic medical record system, EPIC, we reviewed the patients' surveys to identify barriers to care, which included school and life engagement difficulty, lack of mental health resources, food and transportation insecurity, and cultural/language barriers. We also tracked the number of hospitalizations and ED visits before and during the patients' enrollment in NICH. We discovered that through NICH, the aforementioned barriers to care were eliminated, the number of hospitalizations and emergency department visits was reduced, and all patients transitioned from inactive to active on the transplant list. NICH successfully improved the health outcomes of these patients and empowered patients to be more engaged in their care.

Keywords

Pediatric Hemodialysis, ESKD, NICH, Healthcare Disparities

1. Background

ESKD is a lifelong disease, with kidney transplantation being a chronic and

highly technologically dependent therapy. This treatment requires complicated pharmaceutical regimens and interdisciplinary interaction between many specialties, ancillary services, and health insurance providers. Navigating this complex web, which is ever-changing and fraught with barriers, is a challenge for all patients no matter how sophisticated or experienced. Children are especially vulnerable because when young they are completely dependent on their constellation of caregivers. Furthermore, adolescents are subject to developmental changes that predispose them to nonadherence [1]-[3]. Studies continually show that there are social determinants of health, such as structural racism, housing quality, and employment opportunities, that prevent successful outcomes [4] [5]. Therefore, it is important to uncover how to best support families despite these barriers, restoring equity and advancing patient care.

Stanford offers a program that provides a resource for families faced with such barriers. The Novel Intervention in Children's Healthcare (NICH) Program at Lucile Packard Children's Hospital offers free, comprehensive services that delve deeper into the complex medical needs of patients and deliver solutions. This program was originally created by Oregon Health and Sciences University. Enrollment in this intensive program requires that patients meet with a dedicated interventionist to provide individualized attention to improve health outcomes and empower patients. NICH has been successful in many pediatric subspecialty departments. In this retrospective cohort study, we assess how NICH improves healthcare access and quality within our hemodialysis clinic.

2. Aims

Aim 1: To explore if NICH serves as a liaison between the patients and multidisciplinary medical team by tracking the progress of families' engagement with care.

Aim 2: To explore if NICH helps patients better manage the challenges of end-stage kidney disease by reducing the number of hospitalizations and emergency department (ED) visits.

3. Methods

3.1. Data Source

This study used data from the electronic medical record system, EPIC. EPIC includes all patient demographic information, hospitalization and other clinical visits, and any additional documentation from the multidisciplinary medical team.

Through EPIC, we were able to identify patients enrolled in NICH. We reviewed the initial survey submitted by families that highlighted their needs. The surveys focused on school and life engagement difficulty, lack of mental health resources, food and transportation insecurity, and cultural/language barriers. We then reviewed the follow-up surveys up to 1 year after completion of NICH to determine if solutions were delivered for the barriers identified. We also reviewed patients' charts to record the number of hospitalizations and ED visits

prior to and during enrollment in NICH.

3.2. Study Population

Patients enrolled in NICH met the following criteria: 1) needing help to manage the care of a child with a chronic or complex condition, 2) receiving care at Stanford Medicine Children's Health, and 3) living in the greater Bay Area. Inclusion criteria for this study included patients of any age with ESKD requiring hemodialysis who met criteria for NICH. Exclusion criteria included patients with ESKD not receiving dialysis and not meeting criteria for NICH.

Additional consent to participate in this study was not required as patients completed consent forms as part of enrollment in NICH that included agreement to use of patient data for future studies.

3.3. Statistical Analysis

Descriptive statistics were calculated for patient demographics (race, ethnicity, age, and gender), the number of hospitalizations and ED visits prior to and during enrollment in NICH, and the barriers to healthcare before and up to 1 year after enrollment in NICH.

Tables were created to summarize the patient demographics and compare the number of hospitalizations and ED visits before and during enrollment in NICH. A graph was created to highlight the barriers to healthcare before and up to 1 year after enrollment in NICH.

4. Results

We identified 4 hemodialysis patients enrolled in NICH (**Table 1**). 2 patients were female and Black and 2 were male and Latino. The ages ranged 13 - 15 years old. All four patients graduated from the program. One patient withdrew due to the intensive nature of the program.

Table 1. Demographic characteristics and number hospitalizations and ED visit of NICH patients.

Demographic Characteristics	Total Number
Male	2
Female	2
Ages 12 - 18 years old	4
Hispanic	2
Non-Hispanic	2
Black	2
White	0
Hospitalizations/ED visits prior to NICH	16
Hospitalizations/ED visits during NICH	4

100% of patients expressed school and life engagement difficulty due to the challenges with managing end-stage kidney disease; 75% of patients needed mental health resources and experienced language/cultural barriers; 50% of patients had transportation and food insecurity. Through enrollment with NICH, 100% of patients no longer expressed difficulty with the aforementioned barriers, and 75% had decreased frequency of hospitalizations and ED visits. Interestingly, none of the patients were initially active on the transplant list, and 100% are now active (**Figure 1**).

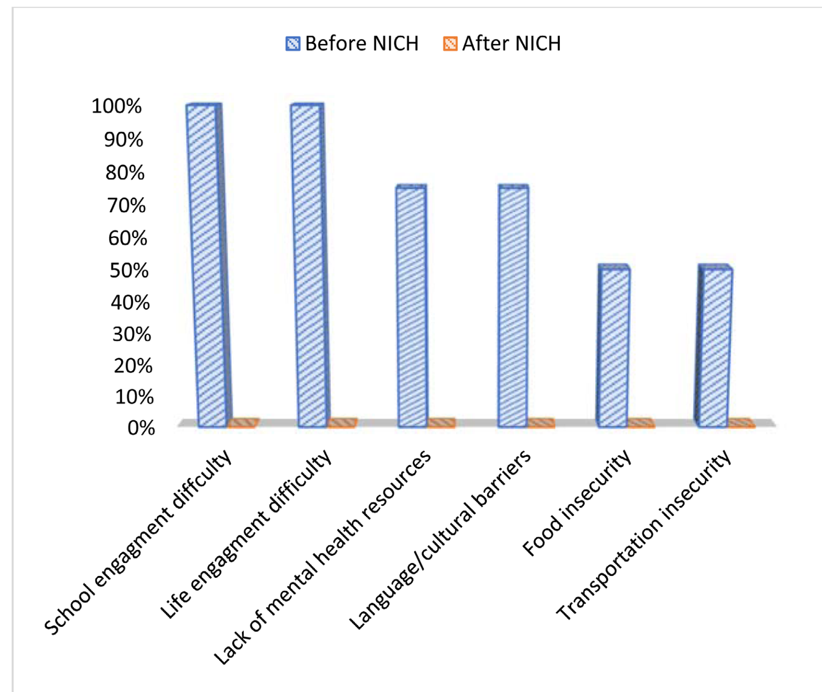

Figure 1. Barriers to healthcare before and up to 1 year after enrollment in NICH.

5. Discussion

ESKD causes a significant burden for families with limited resources [6]. Our study highlights that NICH can support patients with limited resources and optimize their care. Through enrollment in NICH, patients on hemodialysis were able to overcome barriers, such as food insecurity, transportation, and language and cultural barriers, and care was optimized. With regards to race, the patients enrolled in NICH were Black and Latino, and no patients enrolled were White. Black and Latino patients in general experience higher rates of ESKD treated with dialysis as well as lowered transplantation rates compared to White populations [7]. Black and Latino patients are presented with more barriers to care, such as racial and socioeconomic disparities, compared to White patients and unfortunately because of these barriers, care is delayed and not optimized [8] [9]. These patients not only experience delay in care to receive dialysis, but Black and Latino patients also experience delay in undergoing kidney transplantation [10]. Kidney transplantation is the preferred treatment for patients with ESKD,

owing to its improved patient survival, quality of life, reduced morbidity, and economic savings compared with dialysis [10]. Given that Black and Latino patients are placed on the kidney transplantation waitlist later than their White counterparts, their quality of life is decreased, and morbidity and mortality risks are increased.

Black and Latino patients enrolled in NICH were initially listed as inactive on kidney transplantation waitlist. Surprisingly, through the individualized attention provided by NICH, they became active on the kidney transplantation waitlist. This is a significant finding as it highlights that there are racial, ethnic, and socioeconomic disparities that exist for access to transplantation. These patients are often unfairly deemed "medically non-compliant" without addressing numerous barriers they have to overcome to receive care [10]. They are important to address if we want to fully improve health equity.

Additional studies have shown that constraints in healthcare access make it impossible to receive specialized pediatric nephrology care, including dialysis and transplantation. In a recent study by Iorember and Bambobola, the authors highlight there is greater comorbidity, recurrent hospitalization, and a higher mortality rate for patients on dialysis and faced with insurmountable barriers, which further leads to delay in transplantation [11]. Furthermore, Leonard and Grimm highlight that to improve quality of care for more vulnerable populations, the resources provided must prioritize patient safety, timeliness of care, patient centeredness, and efficiency of care. NICH is one program that strives to achieve this goal [12].

Further work should explore more effective strategies to help families with limited resources. Further work should also explore if patients enrolled in NICH have a decreased risk of morbidity and mortality if they are activated on the kidney transplantation waitlist in a timelier manner compared to patients with similar demographics and barriers who are not enrolled in NICH.

We also acknowledge several important limitations of this analysis. First, the study population size was extremely small, and thus, there was not sufficient data to calculate p-values. A larger study population size would improve the significance of this study. Second, there were patients' who met criteria for enrollment in NICH but decided not to enroll due to the intensive nature of the program. Our program is considering how to make the program less intensive to increase participation rates and to ensure that we are adequately reaching patients that need additional resources to help manage such a chronic and complex medical condition. Lastly, patients in our study were only observed one year after completing enrollment in NICH. It would be beneficial to observe patients for at least 3 - 5 years to further investigate the significance of NICH long-term.

6. Conclusion

NICH is essential in improving the health of our patients and preventing inequitable health outcomes. Patients in our hemodialysis clinic were more engaged

with their care, had less frequent hospitalizations and ED visits, and were activated on the transplant list. Additionally, this study further emphasizes the stigma that patients experience when barriers beyond their control, such as cultural differences and socioeconomic factors, limit the care they receive. Improving resource coordination through programs, such as NICH, can best support patients most harmed by healthcare disparities. NICH is committed to that goal and advocates for and empowers patients to receive optimal care.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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