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ORIGINAL PAPER

Identifying Risk Factors Associated with Repeated Referrals Within a Pediatric Navigation Program

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Abstract

Approximately 1-in-5 children have a diagnosed mental, behavioral, and/or developmental disorder or delay by age 8 in the United States. Children with such conditions often require complex, complicated diagnostic and specialty care, making them susceptible to repeated referrals and ongoing unmet healthcare needs. Patient navigation programs (PNPs) are designed to integrate care from primary care providers to community-based services, using trained navigators to help patients and their families manage referrals and connect with referred services. This study examines factors associated with repeated referrals to an active PNP to inform ongoing referral patterns and adaptations to standard navigation support within a large healthcare system in South Carolina (SC). Data is sourced from the inception of the PNP in 2017 through 2022, including 15,702 referrals. Overall, 71.07% had no repeated referrals. Children who are older, diagnosed with attention deficit disorder(s), behavioral concerns, depression, multiple referral needs, and insured by Medicaid were found to be most susceptible to repeated referrals. Conversely, children who are non-Hispanic Black, were referred at a well-child visit, and are primarily insured by private insurance or Tricare were least likely to have repeated referrals. Children who are insured by Medicaid are more likely to be younger, identify as non-Hispanic Black, Hispanic, or another race/ethnicity, and have multiple needs at time of initial referral, identifying a potentially compounded risk for those who hold multiple risk factors to experiencing repeated referrals. Findings may inform adaptations to this PNP model to adjust navigator protocol for at-risk populations and equitably optimize referral-to-service connection.

Keywords Pediatric mental and behavioral health · Patient navigation program · Community health · Health equity · Policy implications

Introduction

Nearly 20% of children have a diagnosed mental, behavioral, and/or developmental disorder or delay (MBDD) by age 8 nationwide [1]. Children with MBDD often require complex and complicated care among primary care providers to appropriately diagnose and refer to appropriate subspecialists—becoming increasingly difficult with multiple co-occurring conditions [2, 3]. Interventions to promote early detection of MBDD, such as universal screening and ongoing surveillance, demonstrate improved long-term health outcomes among patients while also saving approximately $13.00 in longitudinal costs for each $1.00 invested [1]. Further, social drivers of health (SDOH)—including financial constraints, housing instability, and food security—pose significant barriers to accessing care following referral from a primary care provider [4]. Children who receive care within the medical home are privy to effective developmental surveillance and ongoing monitoring, family-centered resources, and tools to support at-risk groups [5–9]. Providers may consider comprehensive diagnostic processes that address patient-specific concerns, while ensuring household- and community-level environments that may influence ability to access referred services and resources [10–12].

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Children referred to mental and behavioral services and their families often struggle to navigate the intricacies of the healthcare system and are potentially vulnerable to experiencing fragmented healthcare that affects their long-term health outcomes and poor satisfaction among patients and their families [2, 4, 13, 14]. Patient navigation programs (PNPs) offer an opportunity to help patients and their families navigate a complex health care system and support healthy development across the lifespan. PNPs demonstrate increased access to quality care across health and community settings, helping children and their families overcome barriers and promoting an integrated care model across service sectors [15, 16]. Repeated referrals to a PNP may be indicative of referrals to multiple specialties concurrently, a fragmented diagnostic process, a need for ongoing care related to a specific condition, or recurrent, untreated concerns among patients and their families [2, 14, 17]. While previous research has suggested differences in healthcare utilization across patient characteristics, very limited, if any, research exists that identifies patient characteristics and insurance coverage associated with repeated referrals within the context of an active PNP.

Pediatric Support Services (PSS) is an active PNP, designed to integrate care from primary care providers to community-based services within a large health system in a southeastern state. PSS employs trained navigators who triage referrals for MBDD and SDOH from primary care providers and provide ongoing support for referral-to-service connection within the health system and community. The purpose of this study is to identify risk factors associated with repeated referrals to PSS to inform ongoing referral patterns and adaptations to standard navigation support. Therefore, the aims of this study are:

1. To examine differences in care pathways, as measured by frequency of repeated referrals, by patient characteristics.
2. To examine insurance-based differences in care pathways, as measured by frequency of repeated referrals.

Methods

Setting and Study Population

This longitudinal study analyzes retrospective data from PSS since its inception. PSS is a systems navigation model where trained navigators triage referrals from primary care providers and provide tailored support to connect children and their families with necessary resources and services within the health system and the community. This healthcare system instituted and supports universal screening within pediatric primary care clinics, including the Survey of Well-being in Youth and Children (SWYC) [18]. Primary care providers who have MBDD and/or SDOH concerns may refer their patients to PSS for ongoing support in connecting with appropriate services. Upon obtaining patient referrals, navigators access patient medical charts and initiate initial contact with patients' legal guardian to identify specific concerns and barriers to care and connect with appropriate services. Navigators document patient outreach encounters in Research Electronic Data Capture (REDCap), a secure, HIPAA-compliant database that stores patient information for translational research [19]. Data included in this study merges REDCap outreach data and electronic health records (EPIC) [19, 20].

This analysis involves data from PSS' inception in September 2017 through April 2023, including patients aged 0 to 18 across 15 primary care clinics systemwide. Through April 2023, PSS has triaged 16,348 total referrals among 13,715 unique patients. Following data cleaning to remove cases with significant outliers and missing data, this analysis includes 15,702 referrals. This study was approved by [Health System Blinded for Review] Institutional Review Board.

Measures

Number of repeated referrals are the primary outcome of interest in this study. Patient characteristics, including age (in years: 0 to < 3, 3 to 5, 6 to 11, 12 to 16, 17 and older), race ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, and Other), biological sex (male/female), and primary insurance coverage (Medicaid, Commercial, Tricare, Self-Pay, or Other) were included as covariates. We hypothesize that receiving the referral at a well-child visit and the number of needs identified at the time of initial referral may be positively associated with their repeated referrals, based on prior research [5, 20–22]. Therefore, these variables were included as covariates as well.

Statistical Analyses

Descriptive statistics were used to examine patient characteristics and understand their distributions per number of repeated referrals within PSS. Chi-square tests and Fisher's Exact Test were used to examine differences in number of repeated referrals by age, race and/or ethnicity, sex, primary insurance coverage, and whether the referral was sourced from well-child visit (Table 1) [16, 23, 24].

Regression analyses were used to examine relationships between number of repeated referrals and (1) patient characteristics and (2) primary insurance coverage. Logistic regression techniques were used to examine differences in patient characteristics, dependent upon primary

Table 1 Characteristics of pediatric support services' population by repeated referrals (N = 15, 702)

	No RR, N(%)	1 RR, N(%)	2 RR, N(%)	3 + RR, N(%)	*p**
	11160 (71.07)	3350 (21.33)	900 (5.73)	292 (1.86)	
Age, N (%)					< 0.001
0 to < 3	2785 (29.65)	617 (21.80)	153 (20.70)	51 (22.87)	
3 to 5	1426 (15.18)	530 (18.73)	156 (21.11)	56 (25.11)	
6 to 11	2370 (25.23)	695 (24.56)	212 (28.69)	61 (27.35)	
12 to 16	2139 (22.77)	774 (27.35)	198 (26.79)	44 (19.73)	
17 and older	674 (7.17)	214 (7.56)	20 (2.71)	11 (4.93)	
Race/ethnicity, N (%)**					0.003
NH White	5646 (61.55)	1797 (64.22)	465 (61.59)	157 (66.53)	
Hispanic	1857 (20.24)	516 (18.44)	139 (18.41)	40 (16.95)	
NH Black	419 (4.57)	97 (3.47)	27 (3.58)	3 (1.27)	
Other	1251 (13.64)	388 (13.87)	124 (16.42)	36 (15.25)	
Sex, N (%)					0.181
Male	5614 (50.47)	1688 (50.58)	477 (53.36)	160 (54.98)	
Female	5508 (49.52)	1649 (49.42)	417 (46.64)	131 (45.02)	
Primary insurance coverage, N (%)					< 0.001
Medicaid	6776 (61.07)	2096 (62.79)	646 (72.18)	208 (71.48)	
Commercial	3478 (31.34)	1025 (30.71)	206 (23.02)	58 (19.93)	
Self-Pay	347 (3.13)	70 (2.10)	16 (1.79)	13 (4.47)	
Tricare	220 (1.98)	64 (1.92)	10 (1.12)	5 (1.72)	
Other	275 (2.48)	83 (2.49)	17 (1.90)	7 (2.41)	
Referral from well-child visit, N (%)					< 0.001
No	2063 (54.91)	635 (61.47)	165 (60.66)	52 (73.24)	
Yes	1694 (45.09)	398 (38.53)	107 (39.34)	19 (26.76)	

RR refers to number of repeated referrals. NH is abbreviated for "Non-Hispanic"

*p-values are calculated via chi-square tests between categorical variables. **p-values calculated via Fisher's Exact Test due to cell value of less than 5

insurance coverage of Medicaid.These analyses were conducted using R, version 4.2.3 [25, 26].

Results

Of those with PSS referrals, 71.07% had no repeated referrals (e.g., they were only referred to mental or behavioral health services one time). A majority of patients included in this analysis were non-Hispanic White (51.36%), reflective of the geographic characteristics of the study location. Additionally, patients were primarily insured by Medicaid (61.94%), and 22.97% aged from birth to 3 years old and 21.26% were among children aged 6 to 11. Significant differences in number of repeated referrals were found by age groups, race and ethnicity, primary insurance coverage, and whether the referral was from a well-child visit ($p < .01$), indicating the need for a closer look at potential risk factors for repeated referrals (Table 1) [2, 14].

Factors Associated with Repeated Referrals

Child's age, race ethnicity, diagnoses of ADD (prior to its exclusion from the DSM-5 [27]) or ADHD, behavioral concerns, depression, referral at well-child visit, number of primary needs at time of referral, and insurance coverage predict repeated referrals (Table 2).

As patient's age increases, patients are more likely to receive repeated referrals (= 0.038, $SE = 0.010$, 95% CI: [0.017, 0.058], $p < 0.001$). Children who are non-Hispanic Black are significantly less likely to have repeated referrals, compared to children who are non-Hispanic White (= −0.104, $SE = 0.040$, 95% CI: [− 0.185, −0.024], $p = 0.011$). As children's number of needs at time of their initial referral increases, their likelihood of receiving repeated referrals increases as well (= 0.025, $SE = 0.011$, 95% CI: [0.003, 0.047], $p = 0.029$). Of referral needs, children with diagnosed ADD/ADHD (= 0.082, $SE = 0.028$, 95% CI: [0.028, 0.136], $p = 0.003$), behavioral concerns (= 0.124, $SE = 0.022$, 95% CI: [0.080, 0.167], $p < 0.001$), and depression (= 0.066, $SE = 0.032$, 95% CI: [0.003, 0.129], $p = 0.039$) are more

Table 2 Strength and significance of effects to predict repeated referrals within pediatric support services' population (N = 15, 702)

Predictor variable	Standardized Estimate (β)	SE	95% Confidence Interval	t-value	*p-value*
Child age	0.038	0.010	[0.017, 0.058]	3.613	< 0.001
Race/ethnicity (Ref: Non-Hispanic White)					
Non-Hispanic Black	− 0.104	0.040	[− 0.185, − 0.024]	− 2.550	0.011
Hispanic	− 0.010	0.028	[− 0.064, 0.044]	− 0.366	0.714
Other	− 0.010	0.029	[− 0.066, 0.046]	− 0.344	0.731
Sex (Ref: Male)	0.000	0.020	[− 0.040, 0.040]	− 0.023	0.981
ADD/ADHD	0.082	0.028	[0.028, 0.136]	2.958	0.003
Anxiety	0.034	0.025	[− 0.015, 0.083]	1.378	0.168
Behavioral concerns	0.124	0.022	[0.080, 0.167]	5.553	< 0.001
Depression	0.066	0.032	[0.003, 0.129]	2.068	0.039
Well-child visit	− 0.043	0.021	[− 0.084, − 0.003]	− 2.090	0.037
Number of identified needs at time of referral	0.025	0.011	[0.003, 0.047]	2.184	0.029
Insurance coverage (Ref: Medicaid)					
Private	− 0.133	0.023	[− 0.178, − 0.089]	− 5.865	< 0.001
Self-Pay	− 0.112	0.049	[− 0.208, − 0.017]	− 2.309	0.021
Tricare	− 0.134	0.072	[− 0.275, 0.008]	− 1.854	0.064
Other	− 0.192	0.073	[− 0.335, − 0.048]	− 2.616	0.009

likely to receive repeated referrals, compared to those referred for family-level stressors. Children who have a diagnosis of anxiety does not significantly increase their likelihood of receiving repeated referrals (= 0.034, $SE = 0.025$, 95% CI: [− 0.015, 0.083], $p = 0.168$). Children who are referred to PSS at a well-child visit are less likely to receive repeated referrals (= − 0.043, $SE = 0.021$, 95% CI: [− 0.084, − 0.003], $p = 0.037$), which may identify an opportunity to offset other risk factors for fragmented care.

Regarding insurance coverage, children who are insured by private insurance are less likely to experience repeated referrals (= − 0.133, $SE = 0.023$, 95% CI: [− 0.178, − 0.089], $p < 0.001$), compared to those insured by Medicaid. Children who are insured by self-pay (= − 0.112, $SE = 0.049$, 95% CI: [− 0.208, − 0.017], $p = 0.021$) and "other" insurance coverage (= − 0.192, $SE = 0.073$, 95% CI: [− 0.335, − 0.048], $p = 0.009$) are also less likely to experience repeated referrals, compared to children insured by Medicaid. There is no significant difference in repeated referrals between those insured by Medicaid and those insured by Tricare (= − 0.134, $SE = 0.072$, 95% CI: [− 0.275, 0.008], $p = 0.064$).

Factors Associated with Medicaid Coverage

Of all referrals triaged through PSS, 61.94% were among those primarily insured by Medicaid (Table 3). As children get older, they are less likely to rely on Medicaid as their

Table 3 Odds ratios to predict medicaid as primary insurance coverage among pediatric support services' population (N=15, 702)

Predictor variable	Odds ratio (OR)	95% Confidence interval	*p-value*
Child age	0.949	[0.935, 0.964]	< 0.001
Race and/or ethnicity			
Non-Hispanic Black	1.170	[1.102, 1.242]	< 0.001
Hispanic	1.158	[1.112, 1.205]	< 0.001
Other	1.119	[1.073, 1.166]	< 0.001
Female	0.989	[0.961, 1.019]	0.474
ADD/ADHD	1.041	[0.999, 1.084]	0.051
Anxiety	0.904	[0.872, 0.937]	< 0.001
Behavioral concerns	0.990	[0.958, 1.022]	0.523
Depression	1.011	[0.064, 1.059]	0.659
Visit type (Ref: non well-child visit)	1.002	[0.972, 1.033]	0.883
Number of identified needs at time of referral	1.033	[1.016, 1.050]	< 0.001

primary insurance coverage (OR = 0.949, 95% CI: [0.935, 0.964], $p < 0.001$). Considering differences by race and ethnicity, children who are non-Hispanic Black (OR = 1.170, 95% CI: [1.102, 1.242], $p < 0.001$), Hispanic (OR = 1.158, 95% CI: [1.112, 1.205], $p < 0.001$), and those who identify with another race and/or ethnicity (OR = 1.119, 95% CI: [1.073, 1.166], $p < 0.001$) are more likely than children who are non-Hispanic White to be insured by Medicaid. Children who have diagnoses of anxiety (OR = 0.904, 95% CI: [0.872, 0.937], $p < 0.001$) at time of referral to PSS are less likely to be primarily insured by Medicaid. Lastly, children are more likely to be insured by Medicaid with each increase in primary needs at time of PSS referral (OR = 1.033, 95% CI: [1.016, 1.050], $p < 0.001$). These factors are important to consider in the context of risk-tiering PSS referrals, as children who are primarily insured by Medicaid are more likely to have repeated referrals and relatively higher number of needs at time of initial referral compared to children who are insured by other insurance types.

Discussion

Differences in Referral Patterns by Demographics

Based on our analysis, patients who are older, diagnosed with ADD/ADHD, have depression, and/or behavioral concerns are most likely to receive repeated referrals to PSS. Within PSS, older children are more likely to have repeated referrals which may account for increased needs over time or disparities in service connection. Children who are older may be susceptible to having repeated referrals due to ongoing mental and behavioral health concerns. However, it is also possible that older children are vulnerable to not connecting with necessary services, and therefore, require more referrals before receiving necessary care. This finding is consistent with other studies within the literature, where age is the most powerful predictor of MBDD and need for referred services [1, 2].

We found children who are non-Hispanic black are less likely to receive repeated referrals, compared to children who are non-Hispanic White. This finding may be indicative of confounding inequities in the health care system, including disparities in access to well-child visits and/or an underdiagnosis of MBDD [22, 26, 28, 29]. Further research is needed to understand differences in referral patterns by race and ethnicity and to acknowledge possible disparities in access to well-child visits within the medical home.

Children with a diagnosis of ADHD and behavioral concerns are more likely than children without MBDD to receive repeated referrals. Behavioral concerns may include children with undetected attention deficits symptomology, which suggests that children with diagnosed ADHD may have greater access to necessary patient- and family-level supports to optimize functional independence and quality of life [30]. Children with depression are also more likely to receive repeated referrals, which is consistent with standards of ongoing care within primary care for this population [31, 32]. These findings reinforce the responsibility of primary care providers to implement early detection and developmental screening for MBDD within the medical home [33]. Existing research demonstrates the promise of this investment, as this may result in improved academic achievement and decreased risky behaviors, suicide risk, unemployment, and health-related costs among patients over time [1, 31, 33, 34].

Differences in Referral Patterns by Insurance

Our findings suggest children with private insurance, Tricare, and who self-pay for healthcare services are significantly less likely to receive repeated referrals to PSS, compared to children who are insured by Medicaid. Pediatric mental and behavioral health services are reimbursed at a significantly higher rate among children with commercial insurance coverage, compared to Medicaid [35]. Among the PSS population, children with anxiety and behavioral concerns are less likely to be insured by Medicaid. National diagnostic guidelines acknowledge that third-party payers often reimburse behavioral and mental diagnostic and treatment services at an inadequate reimbursement rate, compared to services provided [29, 36]. This finding may suggest that children with MBDD concerns have found alternative payment options to bypass insurance barriers, or these children are unable to access appropriate care due to financial limitations. A state-level policy analysis examining differences in access to pediatric mental health services in 24 states suggests that more competitive reimbursement rates among Medicaid-insured children may partially address existing barriers to care [35].

Among children referred to PSS who are insured by Medicaid, children are more likely to be younger, identify as non-Hispanic Black, Hispanic, or another race or ethnicity, and have multiple needs at time of initial referral. Notably, this is consistent with existing research as Medicaid has improved coverage and healthcare access for low-income children and reduced disparities by race and ethnicity [36, 37]. Still, regardless of insurance coverage, these demographic groups are more likely to experience disparities in healthcare access, suggesting that Medicaid coverage may compound the risk of low referral-to-service connection and experiencing fragmented care [11, 36, 38]. Existing research suggests that low physician payment rates, limited accountability of managed care organizations, and failure to allow coverage of full range of intended benefits under federal law may contribute to disparities among Medicaid-insured

children, compared to children insured by other insurance types [36]. Providers and navigators within the medical home may consider insurance type, as well as SDOH often associated with this population, when making recommendations and referrals for ongoing care [4].

PSS Adaptations and Higher-Level Implications

Our findings suggest that those referred through well-child visits are less likely to experience repeated referrals. To translate these findings to practice, primary care providers within the health system may benefit from additional education on PSS navigation capabilities to ensure streamlined referral-to-service connection among patients and their families. Additionally, children who regularly attend well-child visits undergo developmental screening per health system universal screening requirements and receive care within a medical home, which likely better positions them to receive appropriate, timely care [6, 39]. These findings align with existing research which suggests that providers who perform comprehensive, diagnostic evaluation often prevent multiple referrals among children with MBDD [1, 40]. Still, further research is needed to better understand inequities in healthcare access, related to well-child visit compliance and barriers to referred services, within the context of the PSS population.

To enhance provider and navigator capacities, next steps of PSS adaptations may involve a closed-loop referral system, where navigators and providers can monitor patients' connection to referred services within the electronic medical record for seamless care between health system and community [24]. Existing research suggests that integrating mobile health technology, often used to coordinate referrals and specialized care, may promote increased connection to services and improve long-term health outcomes [24]. This adaptation may provide an additional level of support, allowing for regular follow-up by providers, and prevention of repeated referrals and fragmented care experiences among patients and their families.

Considering our findings related to insurance-based differences, navigators may prioritize providing additional resources and follow-up support from referral-to-service among patients and families insured by Medicaid to accommodate for SDOH and insurance-related barriers [11, 36]. Still, despite adjusted risk and navigator support based on insurance, PSS cannot override barriers related to reimbursement rates and failure to cover the full range of benefits authorized under federal law [36]. These barriers are especially relevant to our population, with nearly two-thirds of PSS referrals being insured by Medicaid. Further, PSS is situated within the largest health system in the state where resources are relatively higher than many other counties statewide. Further research is needed to analyze state-level data and quality measurement to assess insurance-based inequities and to identify cost efficient methods of replicating this navigation system and implementing its components statewide.

Limitations

There are several limitations to this study. The data analyzed in this study is sourced from REDCap and, while this database is used to reduce data entry errors, it remains susceptible to error due to partial manual data entry [20]. As a result, race and ethnicity is documented as "Other" for 1,799 referrals, potentially limiting the generalizability of findings related to these demographics. Next steps include PSS adaptions to integrate navigator and provider documentation for seamless translation from the health system to community-based services [24]. Further, "connection to services" is defined in this study as children who have already received or are pending services, including those who have scheduled appointments they have not yet attended. Those who are pending are included in this group due to existing waitlists and service availability, which is not an indicator of navigation quality. This research team is currently conducting a study to follow-up with patients who are pending and identify, if any, experienced barriers to care to enhance navigation services if able. Additional research is needed to test the generalizability of this navigation model with PSS adaptations and within the context of different geographic regions.

Conclusions

Our study found children who are older, with diagnoses of ADD/ADHD, behavioral concerns, and/or depression, and with increased number of referral needs are more susceptible to repeated referrals over time. Children who receive referrals at well-child visits and who are insured by private insurance and Tricare, compared to Medicaid-insured children, are significantly less likely to receive repeated referrals. Future adaptations to the PSS model, including provider referral patterns and navigator support, may be adjusted to optimize referral-to-service connection among identified at-risk groups.

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Declarations

Conflict of interest The authors have no conflicts of interest relevant to this article to disclose.

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