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Vital Initiative to Help Maximize Family Satisfaction in CMC's

Sanford Patient Navigation Program for Children with Medical Complexities (CMC): A Vital Initiative to Help Minimize Costs and Maximize Family Satisfaction in CMC's

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Abstract

It is no secret that medical costs are rising. However, for families with children who have medical complexities, the financial burden is just the beginning of challenges faced daily. However, programs are beginning to develop aiming at minimizing the challenges these families face. One of these initiatives' hospitals continue to improve is the use of care coordination or patient navigation efforts. The Sanford Patient Navigation Program is a new hospital initiative reflecting care coordination models across the country designed to better serve children with medical complexities in our communities.

The project examined the first two cohorts of the Sanford Patient Navigation program. Cohort I consisted of 30 participants and Cohort II consisted of 26 participants, separately. Twenty-eight of Cohort I participants have participated in a post-survey given after completing a year in the program. Cohort II did have additional requirements in qualification: removing the geographical limit and adding a financial eligibility restriction (<200% of the federal poverty level). Between the two cohorts, six areas in the pre-program evaluations stood out to compare including medical home status, care coordination needs, perception of healthcare provider communication, resource challenges, parental distress, and financial burdens. Regarding meeting medical home status, Cohort I showed 83.3% of participants did not meet the criteria for a medical home in the Pre-Program evaluation with 80% of Cohort II not meeting criteria for medical home. A lack of care coordination was the largest reason for a lack of qualifying participants. In Cohort I, 60% of participants needed extra help and did not receive it with 75% of Cohort II facing the same issue.

Keywords: Care coordination, CMC, Children with Medical Complexities, Patient Navigation

Introduction

Childhood is a treasured time for young ones and their families that is full of life, exploration, and adventure. But for children with medical complexities, the focus is not on living for fun, but instead on fighting for the child's chance at life at all. Currently, children with medical complexities represent 1% of the children in the US (Cady et al., 2017). This considerably small group, increasing at a rate of 5% per year, requires a vast amount of intensive care (Gallo, 2021). The intensity of care needed accounts for close to a third of all pediatric health care expenses (Gallo, 2021). Yet, 1 out of 4 of these hospitalizations could be avoided (Gallo, 2021).

One of the first bases of children with medical complexities is the definition of special health care needs. Cordeiro et al. (2018) analyzed the results of 2009-2010 National Survey of Children with Special Health Care Needs finding around 20% or 14 million children are classified with special health care needs. Children and youth with special health care needs (CYSHCN) are defined as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." (Cordeiro et al., 2018). Families with a CYSHCN and the child themselves face countless challenges like unemployment, mental health challenges, financial concerns, development issues, and more. In a 2018 study of CSHCN in South Dakota with 292 respondents, it was found that the mean number of conditions per child was 4.1 conditions with 9.9% having more than seven conditions (Kerkvliet and Molengraaf, 2018). Furthermore, 79.1% of children had at least one chronic physical condition, 64.0% had at least one behavioral health condition, and 50.7% experienced at least 1 developmental delay (Kerkvliet and Molengraaf, 2018). These families face needs in

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many aspects including financial, emotional, education, and more outside of medical. In South Dakota, a couple programs have been developed to help out these families including SD Health KiCC and the federal Maternal Child Health (MCH) Program.

SD Health KiCC is also known as Better Health for Kids with Chronic Conditions. SD Health KiCC aims at providing financial assistance for procedures, treatments, medications, and travel related expenses (Kerkvliet and Molengraaf, 2018). However, enrollment in the SD Health KiCC program has declined significantly over the last few years (Kerkvliet and Molengraaf, 2018). The Maternal and Child Health Program, under the Title V Block Grant, aims at improving the health of women and children (Kerkvliet and Molengraaf, 2018). Specific aims directed towards CSHCNs include six outcomes: 1) early continuous screening, 2) adequate insurance, 3) families as partners in decision-making, 4) access to coordinated care in a medical-home, 5) community-based care, and 6) transition to adult care and services (Kerkvliet and Molengraaf, 2018). Both SD Health KiCC and MCH Program are important programs aimed to better the healthcare of CSHCN's. However, the obstacle lies in the restrictions to these programs to be considered eligible. In the 2016 National Survey of Children's Health, the estimate is that 32,704 children in South Dakota have special health care needs (Kerkvliet and Molengraaf, 2018). Only 13,736 of these children meet the health condition eligibility of SD KiCC and only 7,881 of the thirteen thousand children meet the additional financial restrictions. Though it could be an underestimate, it is valuable to recognize the issue restrictions provide to many families facing challenges.

As previously stated, one of the outcomes of MCHB Program is having access to coordinated care within a medical home. Medical home is defined as "a course of ongoing, comprehensive, coordinated, family-centered care in the child's community" as stated by the

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American Academy of Pediatrics (2002). A medical home then has five separate components: personal healthcare provider, usual source for care like a clinic, family centered care, care coordination, and referrals (Walker et al., 2018). Patient-centered medical homes have been continuously referenced as the way to improving primary care systems as it moves towards a holistic approach to patient care (Hoff et al., 2012).

Patient navigation programs have been developed to improve outcomes, including medical homes for children with special health care needs, with an emphasis on care coordination. Quigley et al. (2014) recognized barriers impacting the care of CMCs including themes of lack of an integrated, accessible, secure platform on which a summary of health care information is stored, fragmentation of the current health system, and the lack of consistent policies and standards for information sharing (Quigley et al., 2014). Though this particular review was focused on Canada, it is still applicable to the United States' needs due to similarity in care provided.

Care coordination addresses all of the barrier themes listed previously. A study by Ramirez et al. (2020), care coordination is a growing solution to the broken health care system and leads to optimizing health care as a whole. The study showed that care coordination improvement led to parent satisfaction, specialist utilization, preventative care for controllable health issues (proper vaccinations), and reduced odds of unmet special care needs (Ramirez et al., 2020). Close to home, Minnesota began a model for care in the state's health care home (HCH) model and used it in statewide healthcare legislation reform (Cady et al., 2015). Out of this program came two models of care coordination, TeleFamilies Model of Pediatric Care Coordination which works in an established HCH and the PROSPer Model of Pediatric Care Coordination which is within a specialty care system (Cady et al., 2015). Within both models, a

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nurse serves as a key component of the care coordination and in turn the success of the program (Cady et al., 2015). The first model, TeleFamilies Model of Pediatric Care Coordination, provided opportunities to test the impact of telehealth technology and increasing nurse involvement in care coordination (Cady et al., 2015). Results included an improvement in overall health care experience and provider communication. PProSPer Model of Pediatric Care Coordination, the second proposed model, looked at connecting primary and specialty care for CMCs (Cady et al., 2015). No matter the program, the value care coordination and patient navigation programs bring to the table is evident not only in increasing the life expectancy of CMCs, but also allowing for a smoother transition to adult care services (Cady et al., 2015).

As of 2019, Australia faced a third of children having complex health care needs (Zurynski et al.). Zurynski et al. (2019) focused on implementing care coordination in tertiary hospital use, which includes referral services or specialty care. The study present interesting results of enrolling families into care coordination by analyzing hospital encounters six months prior and after enrollment. Zurynski et al. (2019) found that care coordination services enrollment prevented an estimate of 557 hospital encounters for 534 children greater than 6 months old. Furthermore, it was found that an estimated AU (Australian currency) \$4.9 million was saved in the pediatric hospital system over the course of two years (Zurynski et al., 2019). This equals about \$3.58 million American dollars. It was also found that 370 school absences and around 31,000 miles, or 50,000 kilometers, of family travel were prevented over the course of two years (Zurynski et al., 2019). In the cross-sectional study, Yu et al. (2020) analyzed the impact of care coordination on CMCs' as well as their caregivers and families. The number of caregiver participant in the study was 136 (Yu et al., 2020). During the 30 days prior to contact for the study, caregivers had a median of 3.5 mentally unhealthy days, increase in depression and

Vital Initiative to Help Maximize Family Satisfaction in CMC's anxiety, and 16 days of insufficient sleep (Yu et al., 2020). However, caregivers and families who had a knowledgeable, supportive care coordinator reported fewer mentally unhealthy days, less anxious, and less depressed with a 95% confidence interval in the statistics (Yu et al., 2020).

Communication and community health care access continue to play a large role in improving the care of those with health disabilities, whether in a child or adult. Communication especially plays a role between providers and the families to allow cooperation. In a study by Walker et. al (2018), 29,845 CSHCN cases in the US were examined to see how meeting the needs of a medical home and care coordination impacted children with special health care needs. In their results (Walker et al., 2018), it was found that 58.3 % met all five criteria for a medical home, and 72% were involved in decision-making. Though these results are better than most, the study still displayed a high number of participants struggling as around 41% of families did not receive coordinated care, 27% did not participate in shared decision-making, and 37% struggled to access community-based programming to help in their child's care (Walker et al., 2018). In 2021, Adams et al. completed a study focused on team communication issues between healthcare providers, families of children with medical complexities, and support services like schools. Common issues included parents feeling frustrated with healthcare technology policies negatively impacting communications with a provider (Adams, 2021). Furthermore, this same frustration was shared between medical team members in the study (Adams, 2021). The second common issue was parents not having adequate access to their child's medical record with the third common issue being a lack of cooperative decision making (Adams, 2021).

In many cases of CMCs, parents often take on a high amount of responsibility as the primary caregiver for their child and tend to be the main care coordinator (Cady, 2017). Many of these parents report high frustration with the communication across the healthcare systems which

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impacts their satisfaction levels towards the care of their child (Cady, 2017). Parents reported the negative toll 24/7 care takes on the family as a whole, jobs, other children, and themselves (Cady, 2017). Foster et al. (2021) gathered similar findings in a systematic interview process of CMC parents. Many (Foster, 2021) reported difficulties conquering everyday obligations like shopping, cooking, and being with CMC siblings. This led to struggles with mental health and general health decline due to a lack of eating healthy or exercising (Foster, 2021). Caregivers of complex children with special healthcare needs reported on average two hours of care coordination per week and between 11-15 hours of direct home care (Kuo, 2011). As the study Walker et al. (2018) showed 24% of families experienced financial hardships, 27.5% families had to cut back on hours or stop working entirely, and 36% shared their insurance was inadequate.

Resource access challenges are relevant issues facing children with medical complexities. It was found that among more complex CSHCN, 15,000 were less likely to get needed medications and that there was a lack of non-medical and community-based resources available (Kuo, 2011). Furthermore, in children three years or younger, 19% (n=9,897,115) of less-complex and 82% of more-complex (n=324,323) CSCHN received early intervention (Kuo, 2011). Indicating though the needs of highly complex CSCHN, there are still 81% "less-complex" CSCHN not receiving their full needs. For ages three to seventeen, only 27% (n=9,897,115) less complex and 77% (n=324,323) more complex CSCHN received special education services (Kuo, 2011). The unmet needs in a medical home and not having family centered care coordination leads to frustration and unmet medical needs. Financial challenges are a common contributing factor to a lack of resources and unmet needs. In a study, 46% of more-complex CSHCN families (n=150,021) shared that they paid more than \$1000 in out-of-pocket

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health care costs in the prior year and 57% (n=184,043) of participating families reported healthcare financial problems (Kuo, 2011). An analyzation of the data in the 2009-2010 National Survey of Children with Special Health Care Needs (Romley et al., 2017), 5.6 million US children with special healthcare needs received 1.5 billion hours of family-provided health care. If replaced with a home health aide, Romley et al. (2017) estimated the value at \$35.7 billion and \$6400 per child per year. If this is inflated to pricing in 2021, this would equal \$7,505.23 at a cumulative inflation rate of 17.3% (Coinnews, 2021). Furthermore, if a family had higher out of pocket expenses, family financial burden, or a greater family work life impact, the likelihood of coordinated comprehensive care decreased.

The Sanford Patient Navigation Program for children with complex medical conditions (CMC) was developed through a partnership with Sanford Children's Specialty Clinic and the South Dakota Department of Health. The program was developed in April of 2020 to combat against the challenges facing the state's children with medical complexity. Children with medical complexities (CMC) are a subset of children with special health care needs. In this subset, CMCs have multiple chronic conditions and tend to need lifesaving technology (Cady et al.). Even though this subset only represents 1% of children in U.S. and Canada, CMCs require a large amount of support and resources (Cady et al.). As shared by Kuo et al. (2016), CMCs may only be 1% of children but make up one third of medical spending across all children due to increasing hospitalizations and hospital admissions. The Sanford Patient Navigation Program for CMCs aims to improve the care of CMCs, reduce expense of families and medical systems, assist with transition of care, and be innovative in providing care to CMCs in South Dakota (Kerkvliet and Jodozi-Molengraaf, Oct. 2021).

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The purpose of this paper is to display and examine the reported needs and medical utilization at enrollment for two Sanford Patient Navigation Program cohorts, which differ by income levels. One-year outcome data for Cohort I will be presented to examine the impact of the program.

Methods

Sanford Patient Navigation Program

The Sanford Patient Navigation Program was able to serve 30 families in the first year making this group the first official cohort (Kerkvliet and Jodozi-Molengraaf, Oct. 2021). In February 2021, Cohort II was developed with a plan to add 50 additional patients. An important part of the program is to include a registered nurse (RN) patient navigator who then serves as the main contact for healthcare professionals, families, and community support programs (Kerkvliet and Jodozi-Molengraaf, Oct. 2021). The RN patient navigator helps with the scheduling of patient appointments, manage post-appointment follow-ups, and is a resource for questions. To be medically eligible to participate in the Sanford Navigation Program, the child must meet all three of the following criteria: 1) medical conditions with three or more organ systems involved, 2) three or more surgical specialists involved in the past year, and 3) five days spent in the hospital in the past year or ten medical clinic visits throughout the year prior to enrollment. Based on these criteria, Sanford estimates around 800 children are eligible for the program.

Instruments and Procedures

Evaluation of Sanford's pilot navigation program used two surveys, one pre-program and another one-year post-program. Survey content included health outcomes, family needs, perceptions of families and medical staff, and family satisfaction with care. The evaluation also

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looked into the role of the RN patient navigator to enhance and maximize the service of the role. The survey participants took had minimal identifiers in constructed questions. Questions in the evaluations included, but not limited to race, gender, age, county of residence, health insurance status, number of medical visits, hospital stays, emergency department visits, and referrals. Questions used to assess medical home were taken from the National Survey of Children's Health, and included having at least one consistent health care provider, a usual place for medical care, ability to easily receive needed referrals, family centered care, and effective care coordination. The project was reviewed by the Sanford Institutional Review Board and assessed as not research. No families were required to complete the evaluation surveys.

Sample

From Cohort I, 30 families agreed to participate in the pre-program evaluation. At this time 28 of the 30 families in Cohort I have completed the post-program evaluation. Eligibility into Cohort I included: meeting the program's medical eligibility outlined above, under 18 years old, must be a resident of South Dakota, and have Medicaid as a primary or secondary insurance or uninsured. There was an emphasis of selecting CMCs from rural communities in South Dakota as a target of 75% enrollees from more than 100 miles from Sioux Falls was established. From Cohort II, the first 30 families of 50 families in the cohort will be the comparison to Cohort I. At the time of this paper, 20 families returned the pre-survey to provide data. Post-program evaluation for Cohort II is planned following completion of a year in the program. Cohort II eligibility differed to Cohort I requirements by eliminating the geographic requirement and additional financial eligibility restriction (<200% of the federal poverty level).

Data Findings

Characteristics of the Sample

The following figure displays the household and insurance characteristics of both cohorts. It is important to note all families in Cohort II reported an income less than 200% of the federal poverty level prior to enrollment. In Cohort I, more than one adult was in 90% of the respondents' homes. In Cohort II, at least one adult was in 85% of the respondents' homes.

Figure 1. Household and Insurance Characteristics

	Household Size		Income	
	<i>Total People</i>	<i>Children</i>	<i>Average</i>	<i>Income Range</i>
<u>Cohort I (n=30)</u>	4.6	2.3	\$71,875.75	\$10,512 to \$180,00 yearly
<u>Cohort II (n=20)</u>	4.0	2.0	\$34,513	\$18,000 to \$63,000 yearly

	Medicaid	
	<i>Listed as Primary and Only Insurance type</i>	<i>Listed as Secondary Insurance</i>
<u>Cohort I (n=30)</u>	16 participants	14 participants
<u>Cohort II (n=20)</u>	20 participants	4 participants

Figure 2 displays the participant characteristics including the mean age, gender distribution, and race. There was a 5.42-year difference between average age of participants and a higher percent of males in Cohort I.

Figure 2. Participant Characteristics

	Mean Age of Participants	Gender		Race	
		<i>Male</i>	<i>Female</i>	<i>Caucasion</i>	<i>American Indian</i>
<u>Cohort I (n=30)</u>	6.7 years old	70%	30%	90%	10%
<u>Cohort II (n=20)</u>	1.28 years old	50%	50%	61.50%	30.80%

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Figure 3 displays the medical characteristics of both Cohorts. Cohort I had a mean of eight cancelled or no-show appointments in the year prior to being in the program with Cohort II having an average of ten cancelled or no-show appointments. Out of Cohort I, 50% of participants had 20 or more diagnoses in the past year with 64% of Cohort II experiencing 20 or more diagnoses in the past year. It is interesting to note that though Cohort I experienced a wider range of medical providers and diagnoses, the average of both areas is higher in Cohort II. Cohort II had significantly higher medical visit days with having 27.12 more days on average.

Figure 3. Medical Characteristics

	Medical Diagnosis		Medical Providers		Medical Visit Days	
	Average	Range	Average	Range	Average	Range
Cohort I (n=30)	23.7	7 to 63	7.8	3 to 19	43.4 days	10 to 141 days
Cohort II (n=20)	26.64	6 to 56	8.24	5 to 14	70.52 days	16 to 170 days

Enrollment (Pre-Survey) Data

Between the two cohorts, six areas in the pre-program evaluations stood out to compare, including medical home status, care coordination needs, perception of healthcare provider communication, resource challenges, parental distress, and financial burdens.

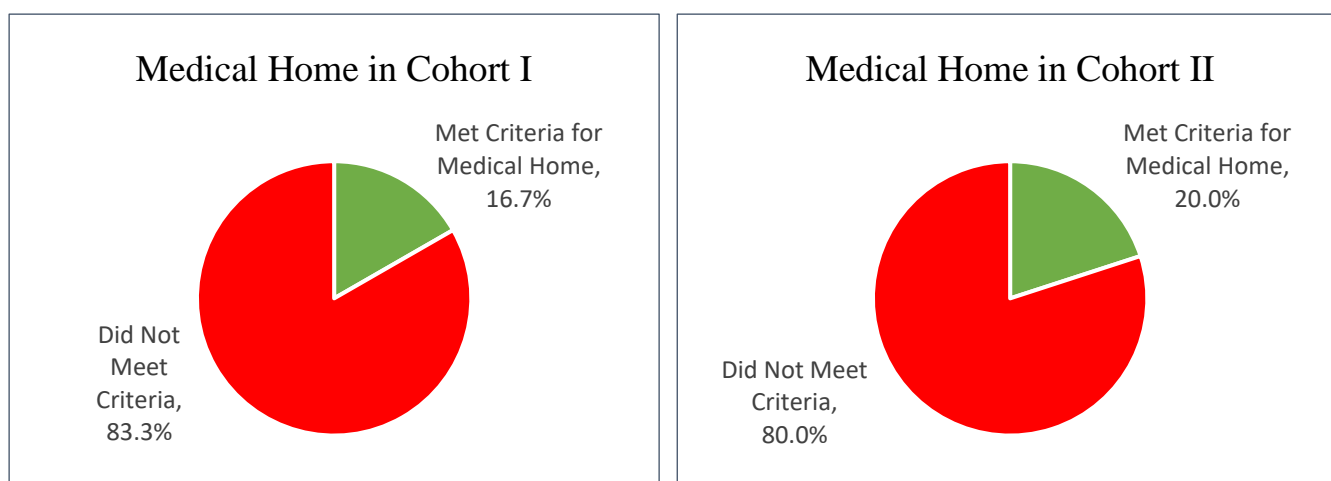
Medical Home Status

Medical homes support improved health care, reduced medical costs, and increases patient satisfaction. Achieving medical home is a national performance indicator through the Maternal and Child Health Block grant (United States Department of Health and Human Services).

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Figure 4 displays the families meeting criteria for receipt of care in a medical home across cohorts. Cohort I results were 83.3% of participants did not meet the criteria for a medical home in the pre-program evaluation. Cohort II shows fairly consistent information as 80.0% of participating respondents also did not meet criteria for medical home based on Pre-Program evaluations. The absence of care coordination serves as the largest deficit to the lack of qualifying participants for a medical home classification.

Figure 4. Families Meeting Criteria for Receipt of Care in a Medical Home Across Cohorts



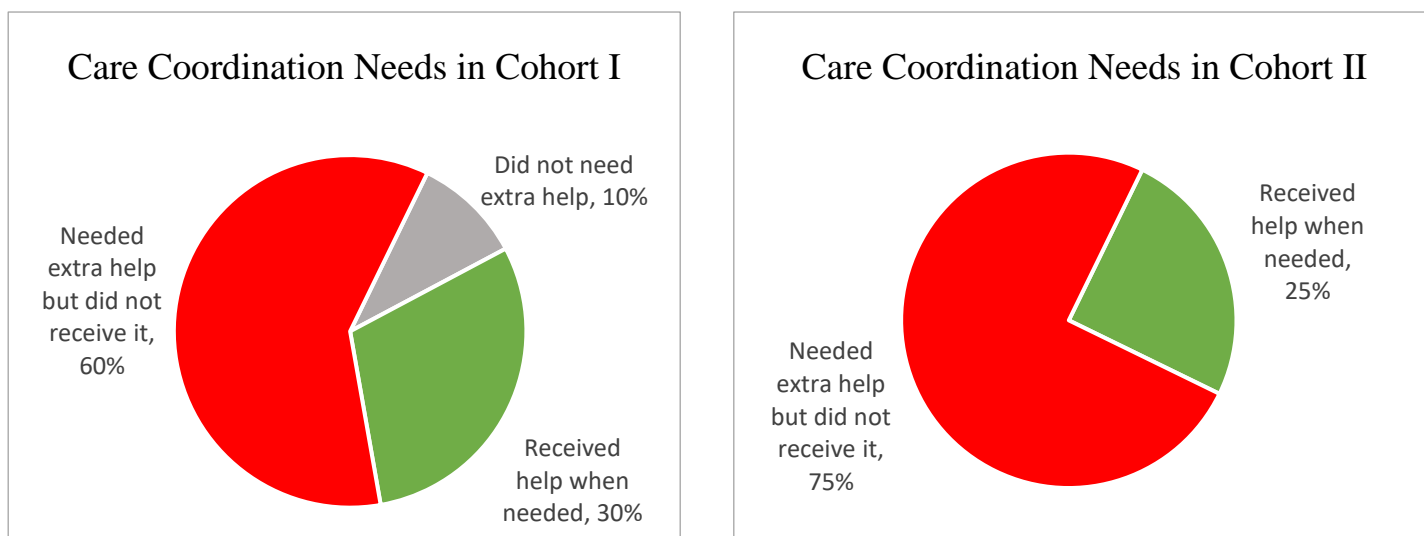
Care Coordination Needs

Care coordination assessed three main factors to determine if the care coordination needs are met, all from the National Survey on Children's Health: extent of extra help in coordination provided, satisfaction with communication across healthcare providers, and satisfaction with communication to schools, childcare, or special education programs. For Cohort I, only 23.3% reported receiving effective care coordination. For Cohort II, only 20% of participating families reported effective care coordination. For both cohorts, the most common person implementing care coordination was a nurse or staff at a provider's office where most signifies 75.0% in

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Cohort I and 60.0% in Cohort II. Figure 5, below, displays care coordination needs across both cohorts. Though 30% of participating families in Cohort I received help when needed and 10% did not need help, 60% of participants that needed extra help did not receive it. Cohort II's data found 75% of participating families needed extra help and did not receive it, up 15% from the previous cohort.

Figure 5. Care Coordination Needs Across Cohorts



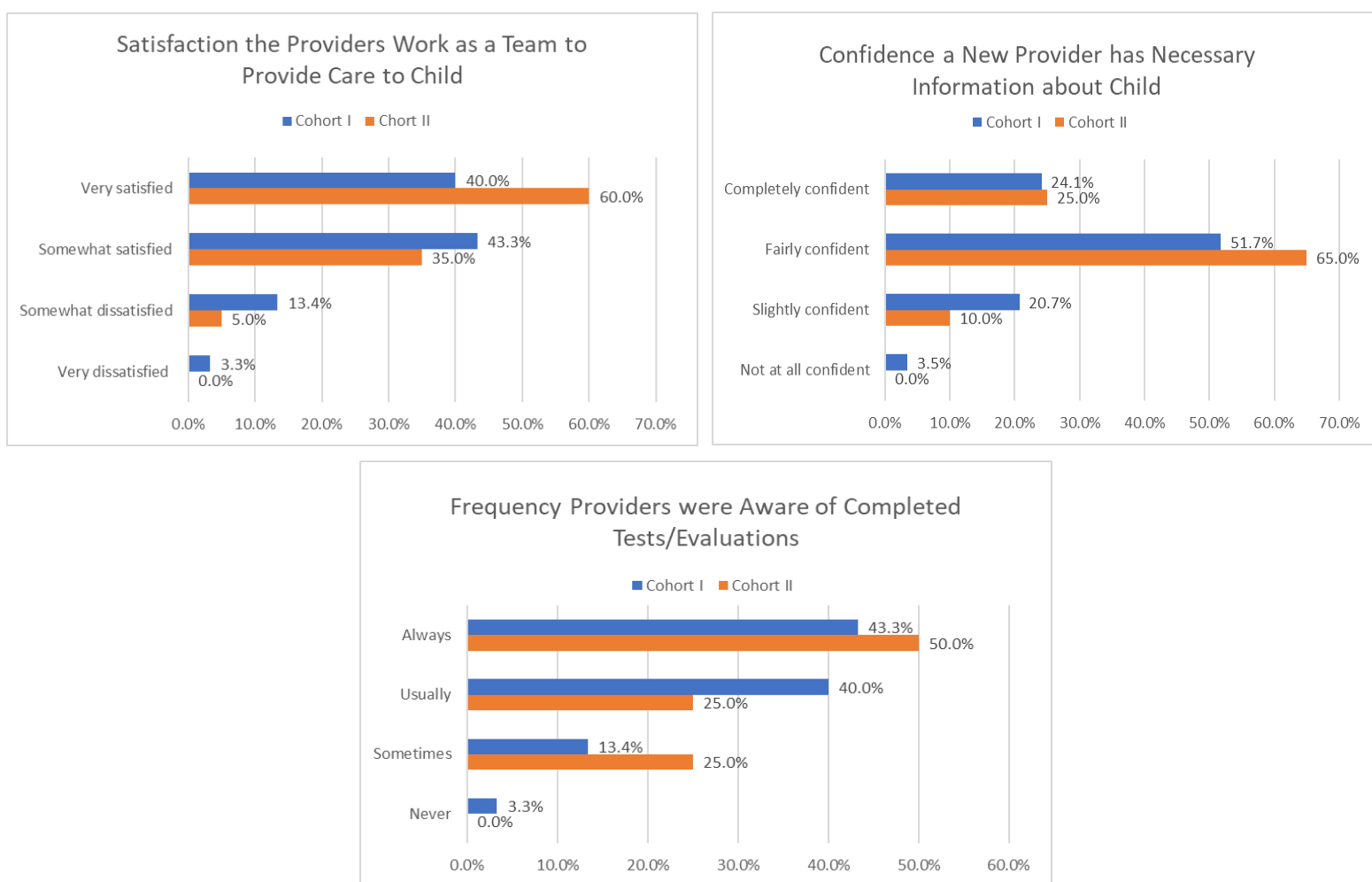
Perception of Healthcare Provider Communication

A factor closely tied into care coordination is communication across healthcare providers and with the families of CMCs. In Figure 6, participating families responded to perceptions of healthcare communication. Cohort II displayed levels of satisfaction across all three questions, with no negative responses (“very dissatisfied”, “not at all confident”, or “never rankings”). Satisfaction ratings on ‘the providers work as a team to provide care to the child’ was high in both cohorts. Many in both cohorts were fairly or completely confident in a provider having the necessary information about a child. This being said, some participants in Cohort I did express

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lower levels of confidence in the provider having the necessary information about a child with 24.2% reporting “slightly confident” or “not at all confident”. Additionally, some participants noted concerns with providers’ awareness of completed tests and evaluation with 16.7% of Cohort I reporting “sometimes” or “never”, and in Cohort II, 25% of participating families responded “sometimes”.

Figure 6. Perceptions of Healthcare Provider Communication

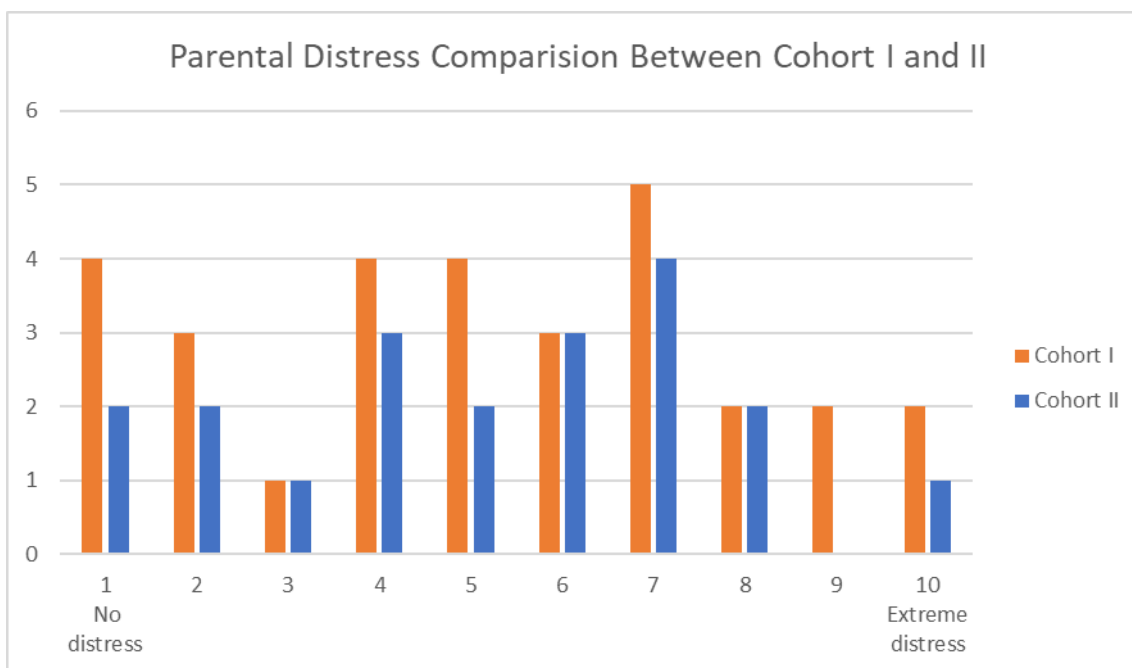


Parental Distress

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In many cases of CMCs, parents often take on a high amount of responsibility as the primary caregiver for their child and tend to be the main care coordinator (Cady, 2017). Only eight out of thirty participating families in Cohort I shared a healthcare team member asked about family impact, while twenty-one families answered “no” or “unsure”. In Cohort II, only eight of twenty responded that a healthcare member had asked while ten reported “no” or “unsure” and one didn’t report. Participating families in both Cohorts were also asked about the overall reported level of stress on a scale of one to ten with ten being “extreme distress”. Figure 7 displays that Cohort I had a mean distress level of 5.2 (standard deviation of 2.7). This was similar to Cohort II which had a mean of 5.0 (standard deviation of 2.5). However, both Cohorts had almost half of participating families reporting a distress level of six or higher, moving towards significant distress. As shown, five families across the cohorts that reported a level nine or ten distress level, indicating significant distress.

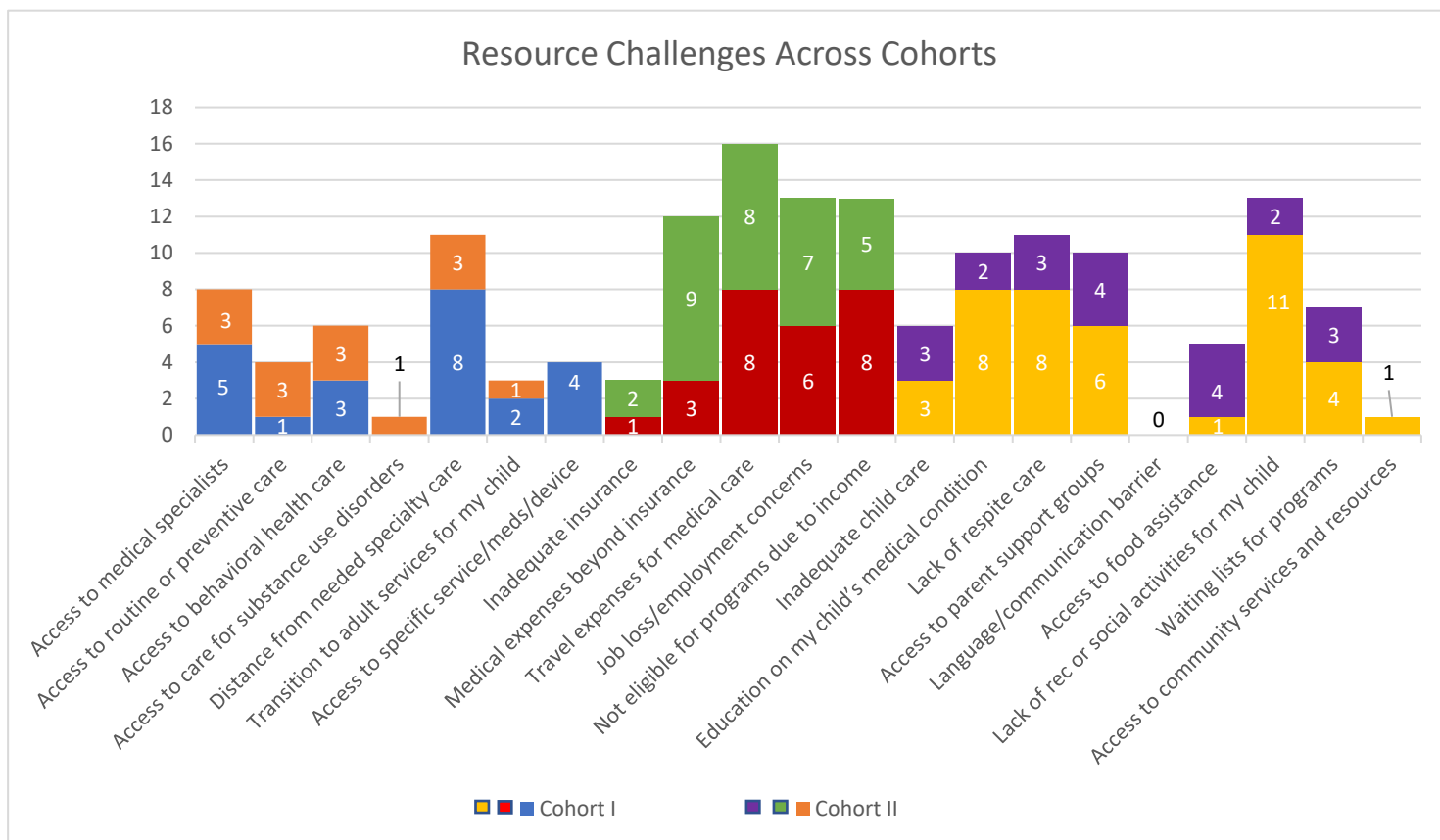
Figure 7. Frequency of Reported Distress Across Cohorts



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Resource Challenges

Resource access challenges serve as continuous issues facing children with medical complexities. In the survey, families were asked about the resource challenges for the child and family among three areas: medical care, financial concerns, and community resources. Figure 8 displays the responses of the families. Four families in both cohorts identified no concerns while the rest had at least one concern. Top Cohort I resource challenges included lack of recreation or social activities as well as a five-way tie between a lack of respite care, education on medical condition, not eligible to programs due to income, travel expenses for medical care, and distance from needed specialty care. Respite care is defined as short term or long-term care of the sick or aging individuals and provides relief for caregivers (NIH National Institute on Aging, 2017). Most insurances do not cover costs for these services, but Medicare will cover a portion of the costs if the respite care is in a hospital or skilled nursing area (NIH National Institute on Aging, 2017). Top Cohort II challenges include medical expenses beyond insurance, travel expenses for medical care, and job loss or employment concerns. Cohort I had top challenges across the three areas: medical, financial, and community resources; however, Cohort II had all top 3 challenges in the financial area of resource challenges. Neither cohort selected "language/communication barrier". Cohort I had the lowest challenge selection for "access to routine or preventative care", "inadequate insurance", "access to food assistance", and "access to community services and resources". Cohort II had the lowest challenge selection for "access to care for substance use disorders" and "transition to adult services". In challenge areas Cohort I scored lowest in, Cohort II tended score higher.

Figure 8. Identified Medical, Financial, and Community Resource Challenges

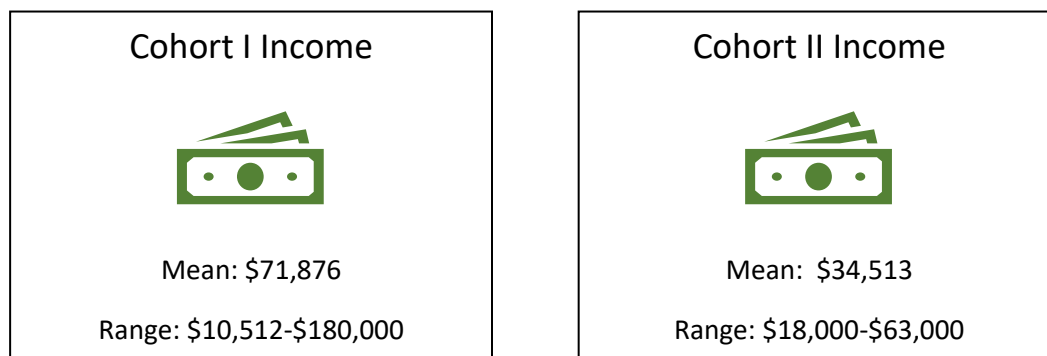
Financial Burdens

Results from this project showed that 20% (n=24) families from Cohort I and 30% (n=20) families in Cohort II reported struggling to pay medical bills. Figure 9 shows the income difference between cohorts, with a \$37,363 mean income difference between the cohorts. Cohort II had an additional financial eligibility restriction (<200% of the federal poverty level) to assess how financial need impacted the perceptions of care coordination and service needs.

Figure 10 focuses on the healthcare related financial burdens between the cohorts. Seventeen of the 30 families in Cohort I and eleven families of 20 in Cohort II identified at least

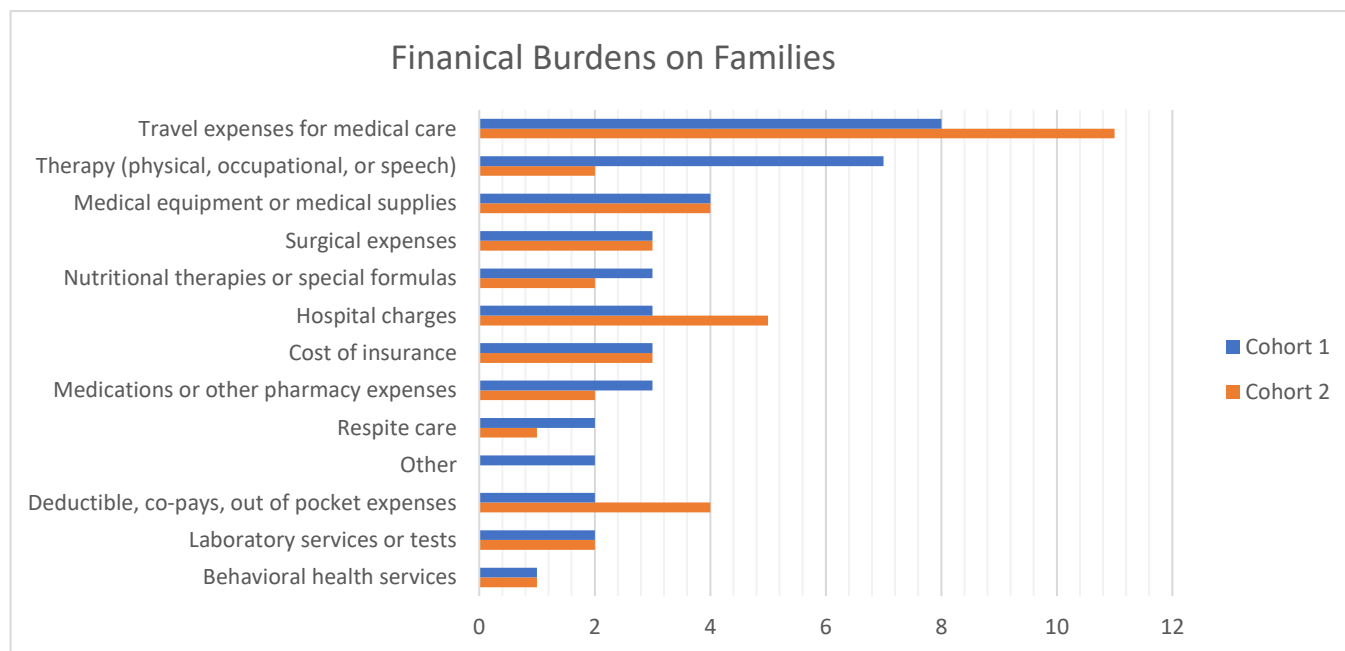
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Figure 9. Reported Income Across Cohorts



least one area of financial hardship. For Cohort I, the top three selected in order included travel expenses for medical care, therapy, and medical equipment or medical supplies. Similarly, Cohort II's top three in order included travel expenses for medical care, hospital charges, and a tie between medical equipment or medical supplies and deductibles, co-pays, or out of pocket expenses. Behavioral health services were chosen by only one person in each cohort.

Figure 10. Healthcare Related Financial Burdens Across Cohorts



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Cohort I One-Year (Post-Survey) Data

As shown in the literature, patient centered care coordination greatly improves the overall satisfaction and care provided to patients. The impact patient-centered care coordination can be seen in the post-survey distributed to Cohort I families. At this point, 22 families have completed the survey thus far. Data comparison between pre- and post- surveys are from Cohort I only.

Medical Home Status

Patient's receipt of care in a medical home greatly improved from only 3 (13.6%) of the 22 post-survey respondents having a medical home at enrollment to 11 (50%) having meet criteria for medical home at the time of post survey. Post-survey numbers are a closer match to 2019-2020 National Survey of Children's Health showing that among CSHCN with more complex care needs, 53.0% met criteria of a medical home in South Dakota (Child and Adolescent Health).

Care Coordination Needs

At enrollment, 59% of families shared they needed help and did not receive it. However, post-survey results showed 91% of the 22 families received help when needed. Succeeding the 2019-2020 National Survey of Children's Health showing that among CSHCN with more complex care needs, where 74.9% received needed care coordination in SD and 68.8% received it nationally (Child and Adolescent Health).

Perception of Healthcare Provider Communication

Communication is a vital aspect to receiving the best healthcare possible for a patient at any medical condition level. Furthermore, the perception of parents or guardians have of the

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communication with and within healthcare impacts the confidence, satisfaction, and cooperation of the patient's caretakers. At enrollment, 27.2% of parents were not confident to slightly confident that a new provider had all the necessary information about their child. A year later in care coordination services brought all participants feeling fairly confident or completely confident in their new doctor's knowledge. 22.7% of parents were very dissatisfied or somewhat dissatisfied in providers working as a team to provide care at enrollment. This number decreased to only 4.5% at somewhat dissatisfied in the post-survey with most (68.2%) being very satisfied. Using communication as a tool to develop a relationship with the caretaker can also develop trust and confidence in healthcare.

Parental Distress

In the pre-survey, only four respondents indicated a member of the healthcare team asked about family impact. This improved to eight individuals in the post survey, but that still leaves most (63.6%, n=22) of families not being checked in on. The lack of perceived connection or support could be influencing the low change in overall parental distress between the pre- and post- survey responses (4.9, SD 2.8 to 4.8, SD 2.1).

Resource Challenges

Many factors play a role in satisfaction, caregiver distress, and perceived ability to give adequate care to their child. The survey approached a handful of these factors by assessing medical, financial, and community resource challenges faced by participating families. In the post-survey, four families identified no unmet needs. However, in families that identified at least one challenge area, there were fewer unmet needs across nearly all areas. Largest changes were seen in "Not eligible for public programs due to income criteria" from eight to three selections,

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“Education on my child’s medical condition” from six to two selections, and “Distance from needed specialty care” from eight to four selections. “Inadequate childcare”, “Waiting lists for programs”, and “Access to routine medical and preventative care” were not selected at all in the post-survey. The only selection exceeding pre-survey results was “Transition and access to adult services for my child”.

Financial Burden

At enrollment, three families reported struggling to pay medical bills and in the post-survey, zero families reported this issue. Regarding specific services creating a financial burden, 11 families selected one or more areas at enrollment. After a year in the program, the post-survey revealed decreases in nearly all the areas with only nine families selecting at least one area. The largest decrease was seen in therapy from five to one selection. Respite care, laboratory services or tests, and hospital charges were not selected at all in the post survey. The only area to increase was medications or pharmacy related expenses. The financial burden on health care systems also improved. In regard to healthcare utilization, the most dramatic change was in the cancel or no-show visits. In a report from 2020, the annual cost of “no-shows” in healthcare is \$150 billion annually (Health Catalyst, 2021). In the pre-survey for Cohort I, the mean of “no-show” visits was 8.1 visits and 4.9 visits in the post-survey. Though not statistically significant ($p=0.059$), the total no-show or cancelled appointments dropped from 213 in pre-survey to 133 in post-survey which greatly saves health companies money.

Discussion

Whether patients and their families fell into Cohort I or II, many challenges still exist in the healthcare system impacting the quality and efficiency of care. This study showed that

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meeting medical home criteria, healthcare provider perceptions, parental distress, health literacy of a child's condition, financial burdens, and developing a plan of care transition into adulthood were common challenges across both cohorts of patients.

The Sanford Navigation program enrolled the first cohort (n=30) in 2020. The RN Patient Navigator quickly addressed over 200 care coordination needs related to these 30 families. When 20 patients in Cohort II came into view, the RN Patient Navigator was able to address over 100 care coordination needs only related to these 20 families. Going forward and based on the findings presented, the Sanford Patient Navigation Program has at least six identified areas of continuing improvement needed.

Medical home is important in ensuring the development of well round and focused care for the patients. Medical homes support improved health care, reduced medical costs, and increases patient satisfaction. Being considered a medical home constitutes satisfactory levels of care in five separate components: personal healthcare provider, usual source for care like a clinic, family centered care, care coordination, and referrals (Walker et al., 2018). Both cohorts showed around 80% of participants not receiving care in a medical home. Though the Cohort 1 Post-Survey did display improvement to only 45.5% not meeting medical home criteria, there is still growth to be had. The main aspect of development is ensuring care coordination which will then in turn continue to develop the other areas.

Perception of teamwork within healthcare is based on the perception families have directly to healthcare providers and indirectly. In both cohorts, a surprising number of participants were not overly positive towards the communication and teamwork of healthcare providers. The largest concerns were involving where or not a provider was aware of tests on the patient (Cohort I= 18.1% and Cohort II=25% chose "never" or "sometimes") and confidence in a new provider

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having the necessary information on a child (Cohort I= 27.2% and Cohort II=10% chose “not at all confident” or “slightly confident”). These levels could be mitigated with a further advancement of an online system to import medical information from both the patient's family side as a symptom tracker and from the provider side. However, utilizing these resources does put responsibility on the provider to review patient summaries. Online medical history should be shared across other organizations as well under the approval of patient families. This lessens the burden of patient families to have to remember every piece of medical history when transferring to a new provider or working with a new clinic. Parents were less concerned with privacy risks and more concerned with the breakdowns in communication (Quigley et al., 2014).

Furthermore, parents need to be viewed as a wealth of knowledge in the treatment and care process. Having parents be actively involved in the care of their child and seen as a resource can improve communication with providers and help in proactive treatment for the patient.

Miscommunications can also cause confusion to the extent of increasing unnecessary urgent care visits or hospital readmissions (Lawrence, 2021).

Mental health and distress concerns reach farther than just the patient with medical complexities, it reaches to the families and caregiver's as well. A caregiver of a CMC sacrifices large amounts of time, energy, and resources to take care of their child. However, these sacrifices often go unnoticed while having a significant impact on other areas of life and family. In an electronic survey of 136 CMC caregivers (Yu et al., 2020), researchers found that care coordination may focus on the CMC's outcomes, it also has the capability of improving the families and caregivers of CMC's. Page et al. (2020) found many parents struggle with constraints on time, lack of sleep, helping siblings cope, and feel they can't leave the house when caring for children who require complex medical care at home. Understanding these challenges

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can guide conversations to help parents feel supported and get proper resources connected. Healthcare providers can improve connecting with the caregivers by shared decision making. Including parents into the conversation on care is important as many want to feel included in decisions (Page et al., 2020). In Cohort I pre-survey, 13.3% reported 'never' or 'sometimes' being encouraged to help in decision making and 25 (n=30) reported 'I don't Know' or 'no' in regard to their awareness of a shared plan of care. In Cohort II pre-survey, 15% reported 'sometimes' being encouraged to help in decision making and 13 (n=70) reported 'I don't Know' or 'no' in regard to their awareness of a shared plan of care. Continued care coordination and other healthcare providers have the opportunity to develop the connection with caregivers, indirectly and directly, leading to improved patient care.

Though the level of health literacy varies across the board, it has been found that a majority has at least some level. However, it is estimated that 35% of the US adult population, or 77 million have low health literacy (Lawrence, 2021). A low health literacy can lead to further poor health outcomes in CMC and in turn lead to an increase in healthcare costs due to preventable medication errors, hospital visits, and stays (Lawrence, 2021). Health care literacy can be improved through care coordination. Both cohorts listed "education on my child's medical condition" as a resource challenge (Cohort I=8 and Cohort 2=2) in the preliminary survey. Yet, Cohort I's number dropped to only 2 selections in the post-survey. Furthermore, out of the 14 participants in Cohort I that mentioned needing assistance with understanding medical instructions for their child's care in the post-survey, 13 were very satisfied due to care coordination meeting this need with one selecting "a little satisfied". Improving the health literacy in patient families is both a provider and a care coordination responsibility. Taking time

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to ask if there are questions, minimize health jargon, directing who to call with questions, and explaining processes can all greatly minimize preventable mistakes down the road.

In the 2019-2020 National Survey of Children's Health, national data showed 10% of participating families struggle paying for medical or health care bills with SD-only displaying 13.7% (Child and Adolescent Health). However, 45% of SD-only reported not receiving health services due to cost with the nationwide data at 54% (Child and Adolescent Health). Health related expenses and resource challenges continue to be a negative factor for both cohorts in the pre- and post- surveys. However, the post-survey for Cohort I provides evidence of decreasing this monetary gap as fewer participants reported financial burdens through the patient navigation program. Travel expenses continues to be the highest-ranking financial burden for CMC families. Telemedicine is a growing opportunity for medical organizations to help lower this burden. In Cohort I, about a quarter of families were interested in all telemedicine types while Cohort II had 45% interested in all types. Further development of telemedicine use could be developed and offered to families interested in repeat visits or initial consults. However, the main concern is that a therapy service wouldn't be received correctly, or a doctor wouldn't see the whole picture. Telemedicine should be done with caregiver input and offered for non-critical appointments.

Further research needs to be conducted on the care services provided and available to CMCs when it comes to a transition into adult care services. South Dakota's national numbers show 57.8% CSHCN with more and 65.3% CSHCN with less complex health needs have not received services needed for transition to adult care services (Child). Yet, discussions with the family should be given early on at the recommended age of 12 years old (Teed et al., 2021). In the pre survey, only one member of Cohort II and two in Cohort I selected a challenge in "transition and

Vital Initiative to Help Maximize Family Satisfaction in CMC's access to adult care services for my child". Selection of this area in the post-survey for Cohort I was consistent with two selections. This would show a consistent need for this service in the future. For proactivity purposes, research and development of a health care plan directed towards transitioning into adult healthcare services should be started.

Limitations of Data

The main limitation of the data relates to the relatively small sample size of the participants in the Cohorts. Furthermore, the specific survey data was only collected from Sanford patients versus multiple hospital systems in South Dakota or the Midwest region.

Conclusion

The Sanford Navigation Program is a launching pad for other facilities in South Dakota to grow and develop care coordination efforts for children with medical complexities. Care coordination of children with medical complexities has the capabilities to reduce present and future medical expenses (Berry et al., 2014) while providing effective care to patients. Lamb (2014, p.xvi), says that care coordination is the "glue that makes the healthcare system a safe and coherent place." Care coordination's overarching purpose is to enable complete care across medical, nonmedical, and service providers (Cady et al., 2020). The intent is to keep the child in their home and community as much as possible through collective collaboration (Cady et al., 2020). Though care-coordination is vital to this specific population, it could be expanded to positively impact other medical areas of health care.

In short, care coordination and the Sanford Patient Navigation program are vital initiatives to further the advancement of patient centered care. Though the survey focused on

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small number, the data from this survey and countless other studies clearly display the positive impact care coordination or navigation programs can have on children with medical complexities and their families.

“[Patient Coordinator] has been phenomenal. I am less stressed out and have had the energy and time to focus on my son and advocate for him because of [Patient Coordinator] help! [Patient Coordinator] finds joy and celebrates successes with us as well as comforts and shows empathy during the hard times! We love [Patient Coordinator]!”

-Post Survey Respondent Comment of the Sanford Navigation Program

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