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Examining early intervention referral patterns in neonatal intensive care unit follow up clinics using telemedicine during COVID-19☆

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ABSTRACT

Background: Neonatal intensive care unit (NICU) follow up programs are in place to ensure infant health and development are monitored after discharge. The COVID-19 Public Health Epidemic (PHE) negatively impacted the ability to conduct in-person NICU follow up visits.
Aims: This study examines using telemedicine in NICU follow up clinics and compares the rates of referral for further medical and/or educational developmental evaluation. A second objective of the study examines if telemedicine can be implemented in the future to ensure access to families while maintaining high levels of caregiver satisfaction.
Method: Data were obtained retrospectively from clinical records from one state's NICU follow-up program. Patterns of referral for further developmental evaluation and caregiver satisfaction prior to the COVID-19 PHE and during the first year of the COVID-19 PHE were examined. A total of 658 NICU follow up visits (384 in-person and 274 telemedicine) were included.
Results: Chi Square analyses revealed significantly more medically related referrals were made during telemedicine visits compared to in-person visits, χ^2 (1) = 5.55, p .05. There were no significant differences between the clinic types in the number of educationally based referrals made, χ^2 (1) = 0.028, p > .05.
Conclusion: The rates of referral for further evaluation made from in-person and telemedicine clinics were comparable, and caregivers were highly satisfied with telemedicine clinic visits. NICU follow up via a virtual platform saves time, money and is equally effective or better in identifying the need for referral for further evaluation.

1. Introduction

Infants who have been discharged from the neonatal intensive care unit (NICU) demonstrate an increased risk of experiencing a developmental delay [1]. Follow up programs for NICU graduates ensure that the health and development of infants in this high-risk population are monitored after the infant is discharged from the NICU. The Individuals with Disabilities Education Act (IDEA) Part C programs are required to implement a comprehensive system of Child Find to identify infants and toddlers with developmental delays and disabilities as early as possible [2]. To find NICU graduates who are not developing like their peers, Nebraska's NICU follow up program partners with The Individuals with Disabilities Act (IDEA) Part C lead agencies as a primary Child Find program to ensure appropriate referrals are made to achieve the goal of identifying developmental delays and disabilities in NICU graduates as early as possible [3]. Comprehensive NICU follow up programs ensure that this high-risk group receives proper evaluation of their development and connect children and families with needed supports and services. Follow up programs serve the crucial purpose of providing caregivers with valuable information about how to navigate the healthcare system with an infant, provide developmental guidance to caregivers, and monitor caregiver mental health and adjustment to life at home with their infant.

The NICU follow up program in Nebraska is a three-tiered model of follow up at three points in time prior to children turning 3 years of age. The model consists of grouping graduates into three levels of increasing

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risk based on medical and social complexity leading to different methods of follow up. Level one, the lowest risk group, is followed by standardized developmental questionnaires, level two children are followed with developmental evaluation in an interdisciplinary clinic, and level three, the highest risk group, with referral to Early Intervention services from the NICU.

Due to the COVID-19 Public Health Epidemic (PHE) many medical services were forced to shift to a virtual platform to continue to provide needed services. Nebraska's NICU follow up program quickly shifted to the use of telemedicine for our Level 2 graduates to complete follow up visits during the emergency declaration. While many follow up programs amended their protocols by using telemedicine, little program evaluation is available to support the use of telemedicine in these programs. DeMauro et al. [4] suggested ongoing program evaluation to determine if developmental delays or medical concerns could be adequately identified using a virtual platform in this population.

The COVID-19 PHE negatively impacted the ability to conduct in-person NICU follow up visits as well as access to referral services. Infants that needed services lacked access because of lockdown guidelines and school closures. There is concern that some vulnerable children have gone unnoticed during the COVID-19 PHE [5]. Studies have shown that during the pandemic, referrals to IDEA Part C (birth to 36 months of age) early intervention systems decreased [6].

The primary objective of the study was to evaluate whether in-person and telemedicine visits in an NICU follow up clinic resulted in similar rates of referral to educational and medical services. A second objective of the study was to examine whether a virtual platform could be implemented in the future to ensure access to families who lived in this predominantly rural state while maintaining high levels of caregiver satisfaction with the clinic experience.

2. Method

2.1. Participants

Data for this communication were obtained retrospectively from clinical records from Nebraska's NICU follow up program. Patterns of referral for developmental evaluation prior to and during the first year of the COVID-19 PHE were examined. The pre-PHE or in-person period was April 1, 2019, through March 30, 2020, and the PHE time period was April 1, 2020 through March 30, 2021. A total of 658 NICU follow up visits were reviewed and included in this study which included a total of 384 in-person visits and 274 telemedicine visits.

2.2. Procedure

The Developmental Tracking of Infant Progress Statewide (TIPS) program provides neurodevelopment follow up for children hospitalized in the 11 participating NICUs in the state and addresses the federally mandated IDEA Part C Child efforts for the state. Parents of all infants with a NICU stay of 72 h or greater are invited to enroll in the three-tiered program. As noted, infants are assigned to one of three risks levels at the time of enrollment. This communication involves only those graduates whose risk would define them as being eligible to be seen in the program's interdisciplinary clinics, our Level 2. Clinic visits are typically offered in-person when children are 6, 16, and 24 months of age when adjusted for prematurity. The in-person clinic protocol includes review of medical history, completion of a comprehensive developmental assessment using the Bayley Scales of Infant Development- third edition [7], and neurodevelopmental screening. Information collected during the clinic visit is used to determine if referrals for educational and/or medical therapies are warranted.

During the COVID-19 PHE, the typical in-person follow up clinic visits were halted in March of 2020; however, the statewide team quickly developed and implemented follow up processes to ensure the needs of children scheduled for clinic during the initial stage of the pandemic were met. From mid-March 2020 through May 2020, families that were scheduled for an in-person clinic visit were notified by the clinic nursing staff that face-to-face visits were cancelled. At that time, the nursing staff gathered information about the child's immediate health, any developmental concerns, and current medical and educational services. Based upon the information gathered and areas of concern expressed by the caregiver, nursing staff triaged children for the next step of follow up. If caregivers expressed concerns about their child's development, a program Developmental Specialist contacted the caregiver to complete a developmental interview and caregivers were provided with developmental guidance and developmentally supported recommendations. Caregivers who indicated concerns about their child's health received follow up from the program's Developmental Pediatrician or Nurse Practitioner, who made needed referrals and sent a summary of the contact to the primary care provider. When caregivers indicated both medical and developmental concerns, the Developmental Specialist or a Pediatric Physical Therapist and a medical provider offered a telemedicine visit to complete health and developmental interviews and observation of the child's developmental skills to determine if additional services/referral were needed. Lastly, if caregivers indicated a concern with behavior, a program Psychologist provided caregiver consultation. Referrals for Part C educational services and/or medical services were made as warranted.

As COVID-19 response and mitigation efforts appeared to be in place for the foreseeable future, the protocol for program clinical services was adapted to ensure families developed and continued established relationships with the program and to ensure children received the comprehensive follow up provided by the program for over 20 years. Beginning in June of 2020, children eligible for a clinic visit were offered a telemedicine visit with the interdisciplinary team. During the telemedicine visit, the team completed the Survey of Wellbeing of Young Children (SWYC) [8]. The SWYC is a comprehensive screening instrument for children under 5 years of age that includes age-specific forms with sections on developmental milestones, behavioral/emotional development, and family risk factors. The SWYC includes screening for parental depression and autism on age-specific forms when age appropriate. The team also completed a caregiver interview to gather health history, current services, and concerns. The caregivers were asked to have the child present during the visit to allow the team the opportunity to observe overall developmental skills in their home setting and request to observe specific interactions and developmental skills to gather additional information based upon the screening results. All information gathered during the visit was utilized to determine if the child needed to be referred for medically based services and/or approval for developmental evaluation for educational services with an IFSP. While this follow up program is funded as a Part C Child Find effort, many Part C programs were closed during the COVID-19 PHE and, therefore, the Nebraska Part C lead agencies acknowledged the potential need to refer to medically based services for children to receive timely evaluation and services during this time. Table 1 includes the typical protocol of in-person visits and those included in the telemedicine visits.

Client satisfaction surveys were provided to caregivers after their clinic visit. The questions surveyed caregivers about their satisfaction on a 5-point agreement scale with *1 strongly disagree* and *5 strongly agree*.

Table 1
In-person v. telemedicine visit protocol.

In-person protocol	Telemedicine protocol
Bayley Scales of Infant Development-3rd edition	Survey of Wellbeing of Young Children (SWYC)
Review of medical history	Review of medical history
Caregiver interview	Caregiver interview
Developmental skill observation (clinical staff facilitated)	Developmental skill observation (caregiver facilitated)

2.3. Statistical analyses

Chi-square analyses were used to determine the relationship between medical and school referral patterns for in-person and telemedicine appointments. Measures of central tendency were used to calculate the average number of miles traveled (round trip) by families to appointments from their city of residence to the city where appointments were conducted. All statistical and descriptive calculations were performed using SPSS Version 27.0.

3. Results

Findings indicated a significant relationship between frequency of medical referrals and type of appointment (in-person v. telemedicine), χ^2 (1) = 5.55, p < .05. Significantly more medically related referrals were made during telemedicine visits compared to in-person visits. Medical referrals were made during 7 % (n = 28) of in-person visits compared to 13 % (n = 35) telemedicine visits.

When examining need for possible school-based services, 12 % of the in-person (n = 46) and telemedicine visits (n = 34) included a referral for school-based services. Therefore, this comparison was not significant, χ^2 (1) = 0.028, p > .05, indicating an equal probability of referral to the school regardless of visit type.

Findings revealed the average distance (round trip) families traveled from their city of residence to the clinic was 144.68 miles. Those who had in-person visits had an average round trip of 161.23 miles and those who had telemedicine appointments would have had a slightly shorter round trip with an average round trip of 121.49 miles.

A total of nine caregivers returned the client satisfaction survey after their in-person visit, and 28 caregivers returned the survey after their telemedicine visits. While the survey return rate was low, both groups were highly satisfied with their clinic services regardless of the service delivery model, with an in-person satisfaction level of 4.96 and a telemedicine satisfaction level of 4.92. There were no caregiver complaints noted.

4. Discussion

Nebraska's NICU follow up program successfully demonstrated that we have served the need of our primarily rural state by implementing a system of Child Find that maintained high referral rates during the COVID-19 PHE using telemedicine.

The protocol used for in-person and telemedicine visits differed slightly to accommodate the mode of service delivery for the developmental portion of the evaluation. With telemedicine, the referral rates were significantly higher for medical services and of equal likelihood of referral for school-based services. Therefore, in this sample of children, it appears that either method of service delivery will result in at least equal numbers of educationally based referrals. The more frequent referrals for medically based services in our telemedicine time may have been secondary to the decreased availability of Part C Early Intervention program services during the COVID-19 PHE resulting from school district closures.

The NICU follow up program quickly shifted to the use of telemedicine to complete follow up visits during the emergency declaration. This shift not only allowed the infants to get needed referrals but also reduced the cost and travel time of those in remote areas [9]. Another key finding in this exploratory report was the efficiency of telemedicine visits. When the COVID-19 public health emergency (PHE) resulted in suspension of in-person NICU follow up visits, it allowed for innovative ways to continue to provide this valuable service. Nebraska is predominantly a rural and medically underserved state. The families included in this report traveled averaged 150 miles round trip for visits, resulting in over 2 h of driving time alone. With the addition of an appointment scheduled for up to 1.5 h plus additional waiting time, families spend at least one-half day involved in the appointment for each follow up visit. The option of having a telemedicine visit may be a solution for families who have a difficult time traveling such a distance, missing work, and driving to visits. Telemedicine saves time, money and is equally effective or better in identifying the need for further referral.

Declaration of competing interest

The authors have no financial or conflicts of interest to disclose.

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