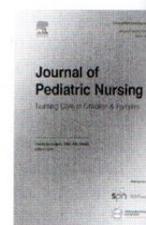




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## Journal of Pediatric Nursing

journal homepage: [www.pediatricnursing.org](http://www.pediatricnursing.org)

## Transition program: Initial implementation with adults with neuromuscular conditions☆

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### ARTICLE INFO

#### Article history:

Received 4 September 2021

Revised 20 June 2022

Accepted 22 June 2022

#### Keywords:

Neuromuscular

Transition

Adult-based healthcare

Pediatric-based healthcare

Cerebral palsy

Interdisciplinary

### ABSTRACT

**Purpose:** To identify current medical and psychosocial needs and to examine the effectiveness of healthcare transition program for adult-aged patients with neuromuscular conditions transitioning from pediatric to adult services.

**Design and methods:** At Neuromuscular Transition Clinic visit, 46 patients were evaluated and referred to adult-based providers, if did not currently have one, from an acquired list of interested clinicians. At mean follow-up of 22 months, 42 were interviewed by phone regarding referrals for Core Services (primary care, physiatry, dental care and gynecology), Medical Specialties and Rehabilitation Services. Mean age was 30 years with 62% males. Majority (74%) had cerebral palsy. Sixty percent were non-ambulatory.

**Results:** As per protocol, all were indicated to need Core Services. Eighty-three percent already had adult primary care provider. Most referrals were given for physiatry (62%), vocational training (100%), and occupational therapy (88%). At follow-up, visits were completed most frequently with adult provider for primary care (100%), occupational therapy (78%), and neurology (75%). Referred provider was seen 100% for physiatry, neurology, physical therapy, occupational therapy and vocational training. Of the total 125 referrals given across all services, 73 (58%) participants had completed a visit with an adult provider.

**Conclusions:** As only about 60% transitioned to adult-based services after referral, healthcare transition remains challenging and requires tailoring of services according to patients' needs, staff and willing-and-available adult-based providers.

**Practice implications:** Transitioning healthcare of patients with neuromuscular conditions from pediatric- to adult-based providers remains challenging. This clinical specialty requires tailoring of services based on patient's needs, and availability of adult-based providers and resources.

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### Background

Health care transition (HCT) for adolescents and emerging adults with childhood-onset neuromuscular conditions (NMC) is a complex undertaking, representing a significant challenge for pediatric- and adult-based healthcare providers. The advances in science and medicine over the past three decades dramatically increased the lifespan for these individuals, but the adult-based health care system lacks the expertise to care for them. The literature shows that HCT has been identified as

a clinical need but the specifications of this clinical specialty are still vague (Bloom et al., 2012; Blum, 1995; Cheak-Zamora et al., 2022; Leeb et al., 2020; Magrab & Millar, 1989). The introduction of the concept of HCT arrived more than two decades ago as a proposed service enhancement for the first generation of adolescents with special health care needs (Betz, 2013).

Blum (1993, p. 570) described HCT as a “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult oriented health-care systems.” In essence, HCT is a clinical specialty practice based on an interdisciplinary healthcare framework covering the adolescents and emerging adults' developmental milestones and movement from different levels of care. This healthcare practice combines the services of multi-health, pediatric- and adult-based specialists who are caring for this unique population. Such that, the pediatric-based healthcare

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providers who work with children and emerging adults are mindful of the developmental stages of early life while the adult-based healthcare providers are acquainted with the middle to final stages of life. Present clinical programs addressing HCT are inadequate and require effective healthcare transition across medical conditions (Bloom et al., 2012; Bolger et al., 2017; Ladores, 2015; NICHD, 2020; Patience et al., 2018).

Thirty years ago, the United States Surgeon General's introductory remarks recognized the developmental needs and long-term survival of adolescents with special health care needs (Koop, 1989). Leaders in pediatric medicine and public health were aware of the health care inadequacies for these children with chronic medical conditions (Betz, 2013). Back then, survivorship to adulthood was limited for children and adolescents with cerebral palsy (CP), spinal muscular atrophy, Duchenne muscular dystrophy, or cystic fibrosis.

Currently approximately 90% of children with chronic health conditions will live into adulthood (Maslow et al., 2011; Mazzucato et al., 2018; Oskou et al., 2013; Pai & Ostendorf, 2011). These young adult patients have a range of healthcare issues arising directly from their medical diagnosis and associated conditions and/or co-morbidities. Like any adolescent approaching adulthood, they have physical, mental, and social changes demanding attention. The adult-based healthcare providers who are assuming the care of this population need to be cognizant of their complicated healthcare needs. A healthcare need arises whenever a patient requires a health service to decrease the impact of their diagnosis or manage their disability.

The awareness of this gap in patients' lifetime care has led to the pursuit of developing programs to address the shortcoming. In an internally funded pilot program, Szalda et al. (2019) utilized a multidisciplinary team to facilitate a system for transitioning patients with medical complexity. The seven-year evaluation of a statewide, state funded transition program stressed the importance of the coordinated interaction of a transdisciplinary team. Although the program was offered to any youth with any health issue, most patients who took advantage of the services had medically or socially complex conditions (Ciccarelli et al., 2015).

In June of 2016, a Neuromuscular Transition Clinic (NTC) was established in an urban, Magnet-designated pediatric orthopedic tertiary care setting in a northeastern United States orthopedic hospital of a university-affiliated medical center. The existing Pediatric Neuromuscular Clinic of the Division of Pediatric Orthopedics provided services to both pediatric and adult patients who were primarily from an underserved population. As these patients were without a plan to transition their care to adult-based providers, the goal of NTC was to transfer all adult patients, with NMC, to adult-based healthcare team and services. For the two years prior to establishing the NTC, relationships were fostered with potential adult-based specialists who were willing to care for this aging population. The Family Nurse Practitioner (FNP) directly contacted, via e-mail and in-person meeting, individual adult-based providers from multiple disciplines to discuss the establishment of new NTC and to ascertain their level of interest in this population. This included providers from the university medical center as well as the community. A resource list of those providers who were available to treat these patients was compiled. The purposes of this study were to identify the current medical and psychosocial needs and to examine the effectiveness of an initial HCT program for a group of adult-aged patients transitioning from pediatric to adult medical and psychosocial services.

## Methods

This case series study was conducted in the NTC, which is part of the Pediatric Neuromuscular Clinic in an orthopedic hospital. From June 2016 to January 2017, patients from the Pediatric Neuromuscular Clinic were eligible for the NTC if they had a visit in the previous two years and were 20 years or older with an NMC. The participants in this study were those patients who completed an evaluation at an NTC visit.

## Program description

At this visit, the NTC team, consisting of an FNP and a social worker, interviewed the patient and caregiver and ascertained the following information: 1) if currently receiving services from primary care provider, psychiatry, dentist, and gynecologist; 2) to determine from reported medical history the necessary medical specialist(s) and rehabilitation service(s) needed by the patient; and 3) to determine which of these services were being provided by a pediatric- or adult-based healthcare provider.

The adult-based services were divided into three categories: 1) Core Services: primary care, psychiatry, dental care, and gynecology; 2) Medical Specialties: spine (orthopedist specializing in spine), neurology, pulmonology, neurosurgery, gastroenterology, genitourinary, and mental health; and 3) Rehabilitation Services: physical therapy, occupational therapy and vocational training. The role of adult-based psychiatry services was to provide the general management of patient's NMC and refer to orthopedics and rehabilitation services as needed.

The four core services were considered to represent the minimum medical needs of any patient. Therefore, the clinic staff ensured that all patients already had an adult-provider or were given referrals for each of these services. For those patients who were receiving pediatric services, referrals to adult-based providers, utilizing the acquired list of resources, were provided. As the patients also had issues that were not being currently addressed, referrals to appropriate adult-based providers were given. No follow-up appointments or phone calls were systematically scheduled.

## Data collection

In the summer of 2018, a follow-up phone call was made by the same NTC's FNP to the patient or same caregiver, at which time the respondent provided verbal consent, in this Institutional Review Board approved study. Medical interpreter services were used as needed. A maximum of three phone call attempts was made.

Prior to the phone call, each patient's NTC visit chart was reviewed for demographics, Gross Motor Function Classification Scale (GMFCS) level (Palisano et al., 1997, 2008), and a list of the services for which the patient had received a referral. In this study, all participants were given a GMFCS level in order to utilize a language commonly used to describe gross motor ability. The GMFCS is the most accepted and utilized of all the functional grouping in CP. The GMFCS is a valid and reliable, five-level rating method to describe the gross motor function of an individual with CP. For example, each level of GMFCS describes self-initiated movements and use of assistive devices (i.e., crutches, walkers, or wheelchair) for mobility. Initially, the GMFCS was designed for ages 2 to 12 years. In 2008, Palisano and colleagues expanded and revised the GMFCS to include 12- to 18-year-olds with descriptors and distinctions in view of their developmental milestones.

For each of the specific referred services, the patient/caregiver was asked if they had completed a visit with an adult provider and if they had used the referred provider. If a patient had not followed through with the NTC visit recommendations, the clinic's FNP re-educated the patient or caregiver on HCT rationale and provided the adult-based resources as needed. If any barriers or difficulties in obtaining the NTC visit recommendations were reported, a referral to the NTC's social worker was initiated.

## Data analysis

Descriptive statistics for participants' demographics were determined. The frequency and percentage of participants were found for the five levels of the GMFCS. For each service, the frequency and percentage of participants were calculated for needed service, already had adult provider, referral given, completed visit with adult provider and saw referred provider.

## Results

Forty-six patients with NMCs had an NTC visit. Forty-two of the 46 patients (91%) were interviewed by phone at a mean length of follow-up of 22 months (range 17–30). Three patients did not return calls and one was unable to participate due to a family issue. The interviewees were: 18 patient only, 1 patient and caregiver, 20 mother only, 2 grandparent and 1 older sister. An interpreter was required in 7 cases, all Spanish.

The mean age at follow-up was 30 years (range 21–49) with 26 (62%) males and 16 (38%) females. The patients' diagnoses included 31 (74%) with CP, 3 (7%) with spina bifida, 2 (5%) with traumatic brain injury, 2 (5%) with arthrogryposis, and 4 (10%) with other NMCs. The patients were classified on the GMFCS as follows: Level I 7 (17%), Level II 4 (10%), Level III 6 (14%), Level IV 11 (26%), and Level V 14 (33%) (Table 1). Seventeen (40%) were ambulatory (Levels I–III) and 25 (60%) were non-ambulatory (Levels IV–V).

As per NTC protocol, all the patients ( $n = 42$ ) were indicated to need primary care, physiatry, dental care, and gynecology (females only,  $n = 16$ ) as shown in Fig. 1 for the Core Services. The frequencies and percentages of participants who 1) needed the service, 2) already had an adult provider, 3) were given a referral to an adult provider, and 4) had completed a visit with an adult provider, either one of their own choosing or the one referred at NTC, are presented in Fig. 1 for the Core Services and in Table 2 for Medical Specialties and Rehabilitation Services. The total number of referrals for Core Services was 57, for Medical Specialties was 13 and for Rehabilitation Services was 55. The total number of completed visits with an adult provider for Core Services was 32, for Medical Specialties was 7 and for Rehabilitation Services was 34. Therefore, for all services, a total of 73 out of the 125 referrals (58%) had completed a visit.

Less than 20% required pulmonology, gastroenterology, genitourinary, and mental health services. Eighty-three percent ( $n = 35$ ) already had an adult primary care provider and 100% already had an adult provider for neurosurgery ( $n = 13$ ), gastroenterology ( $n = 2$ ), and genitourinary ( $n = 4$ ). The most referrals were given for physiatry ( $n = 26$ ; 62%) and rehabilitation services of vocational training ( $n = 17$ ; 100%), occupational therapy ( $n = 23$ ; 88%) and physical therapy ( $n = 15$ ; 83%). The patients most frequently had completed a visit with an adult provider for primary care ( $n = 7$ ; 100%), occupational therapy ( $n = 18$ ; 78%), neurology ( $n = 3$ ; 75%), dental care ( $n = 12$ ; 67%), and spine ( $n = 4$ ; 67%).

Of the patients who had completed a visit with an adult provider, Table 3 includes the frequencies and percentages of the visits in which the adult provider was the one referred at the NTC visit. For physiatry, neurology, physical therapy, occupational therapy and vocational training, 100% used the referred provider. Less than 10

patients were referred to social worker for additional assistance. They had reported barriers to transitioning including development of medical co-morbidities, exacerbation of associated conditions, change in healthcare insurance, and/or significant change in family dynamics.

## Discussion

A visit to the NTC by a group of adults, who were still being followed at a pediatric neuromuscular clinic, was used to identify their medical and psychosocial needs to facilitate their transition of care to adult-based services. The NTC team designated the Core Services of primary care, physiatry, dentistry, and gynecology as being the basic medical needs of any patient with neuromuscular conditions. Therefore, the clinic staff ensured that all patients in NTC either already had an adult provider or provided a referral for each of these services. In our program, the adult-based physiatrist provides the adult patient's overall rehabilitation and neuromuscular management, while the pediatric orthopedist's role converts to a specialty consult service for adult patients with NMC.

The major benefit of NTC is to increase readiness of patients with NMC and their families in transferring the care from pediatric- to adult-based health services. This encompasses the referrals to medical specialists aligned to patient's diagnosis and associated conditions. Additionally, NTC addresses the patient's psychosocial needs including insurance benefits, young adult programs (e.g., college or job preparation), and caregiver classes for community resources. Ultimately, the objective of NTC is to provide continuity of care when a pediatric patient with NMC progresses into adulthood.

As the age of this current group of patients was in the adult range, the majority of participants already had an adult primary care provider and only a few required referrals. They may have had to find an adult provider because their age exceeded the range of pediatricians' scope of care. How they located an adult primary care provider was not addressed in the NTC visit, but possibly they started using their parents' provider or they located a PCP within their nearby community. By the time of follow-up, all patients had seen an adult primary care provider with 71% of them using the referred one.

The high frequency use of the referred provider confirmed the importance of having an available list of resources to share with the patients and their caregivers. As part of developing the NTC, the pediatric clinicians established connections with adult providers, of various disciplines, who were interested in continuing the care of adult patients with NMC. This was considered to be an essential preparatory component prior to implementing the NTC program. However, the data were not collected in this study to determine if patients would have made an appointment with the needed provider in the absence of NTC's referral to available clinicians or service. In a recent study, Razon et al. (2019) had similarly observed that an experienced and resourceful team, whose responsibilities included locating appropriate adult providers, was necessary to address the transition needs of patients with medical complexity.

Although less than half of those receiving a physiatry referral completed a visit, all of them saw the referred physiatrist. Similarly, when a patient decided to address a recommendation for neurology, physical therapy, occupational therapy and vocational training, they always used the referred provider. Most of the time, the referred provider was within our institution, suggesting the ease of access may be a contributing factor and/or trust that we curated the most qualified adult-based provider specific to their need. For the remainder of the referrals, half or close to half saw the referred one when completing a visit.

More than 50% of patients already had an adult dentist and more than 60% of females already had a gynecologist, but less than 40% had a physiatrist. For those patients who had been given a referral, the compliance rate varied with about two-thirds of patients completing a dental visit and only one-third completing a gynecological visit. In the U.S., the

**Table 1**  
Demographics.

	n	%
Gender		
Male	26	62
Female	16	38
Diagnosis		
Cerebral Palsy	31	74
Spina Bifida	3	7
Traumatic Brain Injury	2	5
Arthrogryposis	2	5
Other	4	10
GMFCS <sup>a</sup>		
Level I	7	17
Level II	4	10
Level III	6	14
Level IV	11	26
Level V	14	33

<sup>a</sup> GMFCS, Gross Motor Function Classification Scale.

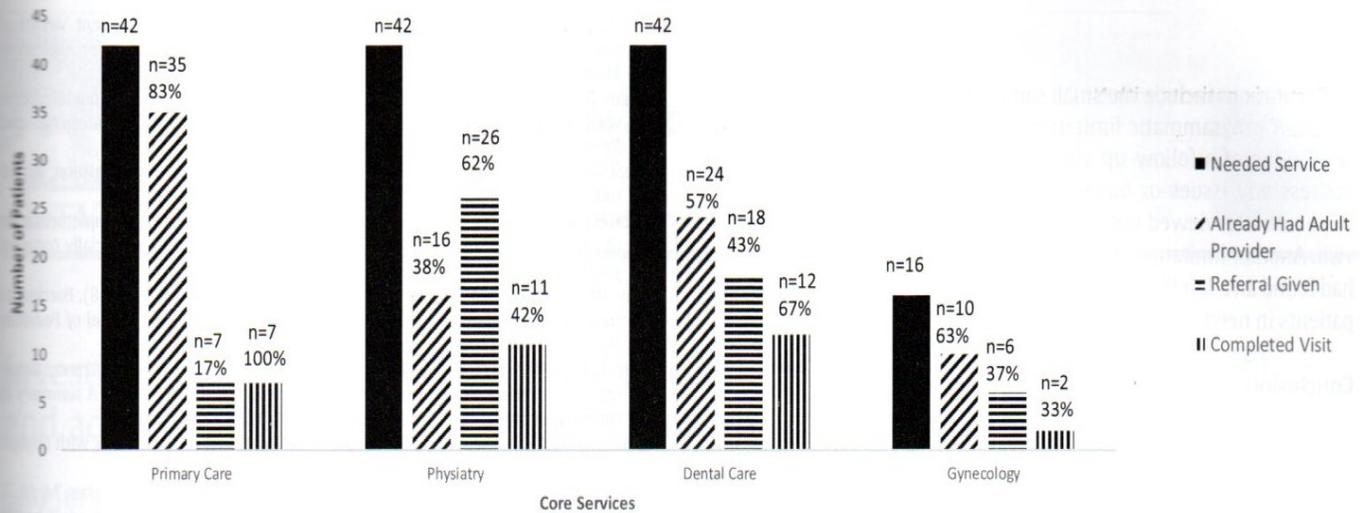


Fig. 1. For each of the Core Services, 1) all patients were considered to need these services, 2) percentage of patients who already had an adult provider, 3) the percentage of patients who were given a referral because did not have an adult provider, and 4) of those who were given a referral, the percentage who completed a visit with an adult provider.

young individuals with disabilities are the leading minority population lacking adequate dental care (Waldman et al., 2017). Women with disabilities have unmet gynecologic care needs i.e., cancer screening and contraceptive care, when compared with women without disabilities (Sonalkar et al., 2020; Wilkinson & Cerreto, 2008). Further, these women are susceptible to disparities of gynecologic care likely because of untrained healthcare providers, unequipped gynecology clinic, lack of education among patients and/or caregivers, and the fractional participation of patient and/or caregiver in gynecology care decision-making. To date, it is undefined how women with disabilities and healthcare providers should team up to meet this appropriate care (Sonalkar et al., 2020).

Of the Rehabilitation Services, occupational therapy (62%) was the most needed followed by physical therapy, and vocational training. Referrals were given for all of these patients for vocational training and greater than 80% for both occupational and physical therapy. Occupational therapy was the most frequently completed referral while physical therapy was the least. The increased compliance rate of occupational therapy referrals was likely attributed to the participants/caregivers often reported concerns regarding equipment, including wheelchairs, based on their GMFCS levels i.e., IV and V.

The majority of patients requiring medical specialty management were already linked to adult-based providers with the exception of patients needing referral to adult-based specialties such as spine (55%), mental health (40%), neurology (25%) and pulmonology (14%). The actual number of individuals involved is low, ranging from 1 to 6. An adult

provider was seen in 4/6 cases for spine and 3/4 for neurology, but not seen for the one pulmonology or two mental health cases. In our institution, pediatric-based providers of spine, neurosurgery, and pulmonary specialty deliver care continually from childhood through adulthood. Mental health services remain a challenge due to lack of available adult-based providers and/or programs.

Patients and caregivers had reported that medical, psychosocial, and personal issues had interfered when transferring their care. In a recent systematic review, Gray et al. (2018) categorized transitioning barriers that patients with chronic illness had encountered into the following five domains: relationships (e.g., pediatric provider unable to let go); access (e.g., unavailable adult providers to continue care); beliefs (e.g., transfer to adult services as a negative event); knowledge (e.g., limited information on transition process); and skills (e.g., lack of self-management skills).

Practice implications

Transitioning healthcare of patients with neuromuscular conditions from pediatric- to adult-based providers remains challenging. This clinical specialty requires tailoring of services based on patient's needs, and availability of adult-based providers and resources.

Table 2  
Frequencies and percentages for Medical Specialties and Rehabilitation Services.

Services	Needed Service		Already Had Adult Provider		Referred to Adult Provider		Completed Visit with Adult Provider	
	n	%	n	%	n	%	n	%
<b>Medical Specialties</b>								
Spine	11	26	5	45	6	55	4	67
Neurology	16	38	12 <sup>a</sup>	75	4	25	3	75
Pulmonology	7	17	6	86	1	14	0	0
Neurosurgery	13	31	13	100	-	-	-	-
Gastroenterology	2	5	2	100	-	-	-	-
Genitourinary	4	10	4	100	-	-	-	-
Mental Health	5	12	3	60	2	40	0	0
<b>Rehabilitation Services</b>								
Physical Therapy	18	43	3	17	15	83	6	40
Occupational Therapy	26	62	3	12	23	88	18	78
Vocational Training	17	40	0	0	17	100	10	59

<sup>a</sup> Includes one who continued to be followed by pediatric neurologist.

Table 3  
Frequencies and percentages of saw referred adult provider.

	Completed Visit with Adult Provider		Saw Referred Adult Provider	
	n	%	n	%
<b>Core Services</b>				
Primary Care	7	71	5	71
Physiatry	11	100	11	100
Dental Care	12	42	5	42
Gynecology <sup>a</sup>	2	50	1	50
<b>Medical Specialties</b>				
Spine	4	50	2	50
Neurology	3	100	3	100
Pulmonology	0	-	-	-
Neurosurgery	-	-	-	-
Gastroenterology	-	-	-	-
Genitourinary	-	-	-	-
Mental Health	0	-	-	-
<b>Rehabilitation Services</b>				
Physical Therapy	6	100	6	100
Occupational Therapy	18	100	18	100
Vocational Training	10	100	10	100

<sup>a</sup> Includes only the 16 females.

## Limitations

Limitations include the small sample size and lack of a comparison group. A programmatic limitation was not including the systematic scheduling of a follow-up visit or phone call to more immediately address any issues or barriers encountered. Patients or caregivers were not interviewed until a minimum of 17 months after their NTC visit. Another limitation was that we did not ascertain how participants had found an adult PCP on their own, which could be beneficial to future patients in need of an adult PCP.

## Conclusion

With one NTC visit, across all services, only about 60% saw an adult provider subsequent to referral. Of those, 84% went to the referred provider. All considered, healthcare transition for patients with NMC, as a clinical specialty, remains vague and challenging. Developing an NTC requires tailoring its services according to the needs of patients, willing-and-available adult-based providers, resources, and staff. The information acquired from the study will serve as the foundation of the NTC as the pediatric clinicians begin to introduce HCT to patients with NMC and their caregivers at early adolescence.

## Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## Conflict of interest

None of the authors has anything to disclose nor conflict of interest.

## CRediT authorship contribution statement

**Eduardo del Rosario:** Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Visualization, Supervision, Project administration. **Adella Bodden:** Investigation. **Debra A. Sala:** Methodology, Formal analysis, Writing – review & editing. **Aline Goodman:** Investigation. **Connie Lam:** Investigation, Writing – review & editing. **Mara Karamitopoulos:** Writing – review & editing.

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