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Delays and Disabilities: NP Screening and Care Management

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Abstract

Neurodevelopmental Disorders (ND) impair functioning and are associated with increased physical and psychological health risks. ND care is increasingly being provided by NPs in primary care settings. To assess NP's knowledge and care management practices for pediatric patients with potential or existing ND, practicing NPs in North Carolina were invited to complete an online survey. NC NP's provide care to ND patients in a variety of settings and have varied levels of experience with ND. Differences in knowledge, screening, and management practices are identified. Methods for improving outcomes and supporting NPs providing care for this at-risk population are discussed.

Introduction

Persons with Neurodevelopmental Disorders (ND) often experience earlier onset of illness and poorer overall health compared with the general public. They suffer higher rates of poor nutrition and obesity and require increased education and health services.¹

Unfortunately, a large percent of primary care providers do not receive training regarding the unique health care issues, needs, and challenges people with NDs face.² Without the exposure to education about evidence-based care practices for this population, negative attitudes about caring for this at-risk population can occur. Thus, health care disparities exist for those affected by ND. With new federal mandates moving care for persons with ND from institutions to community living environments greater care responsibilities will be placed on primary care clinicians.³

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Medical Definition

Neurodevelopmental Disorders (ND) is a group of conditions which impairs a person's personal, social, and academic or occupational functioning.⁴ With the release of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), two groups comprise Neurodevelopmental disorders. In the first group, the onset occurs during the developmental period and in the second, the onset occurs in adulthood. This study relates only to those conditions which arise during the developmental period.

Background and Significance

Nurse Practitioners (NPs) provide care for individuals with ND in a variety of settings including pediatric, family, and psychiatric mental health (PMH) practices. Increasing the skills and understanding of health care providers may serve to build partnerships between providers and persons with ND and help create a health care environment for this population that promotes and protects their well-being. The purpose of this study is to gather information about the current knowledge and care management practices of NPs with regard to children and adolescents with potential or existing ND in North Carolina (NC).

Nationally, one out of every six children has one or more developmental disabilities.⁵ Overall, boys have a higher prevalence of ND than girls (18.04% vs. 9.5%) and the lowest prevalence by ethnic group is in Hispanic children (10.65% vs. Non-Hispanic White 14.99% and Non-Hispanic Black 14.77%).⁵ Further, upwards of 50% of children with ND have an associated emotional disorder.⁶ The top five chronic pediatric conditions and disorders are now developmental and behavioral disorders. Between 37–39% of children will be diagnosed with an emotional or behavioral disorder by age 16 years and 25–40% of those children will have at least one other diagnosis related to mental or behavioral health at any given time.⁷ Less than 30% of children or adolescents with or without ND who are affected by mental health problems receive treatment and this problem has been linked largely to inadequate screening and early intervention by primary care providers.⁷ Availability of qualified providers and awareness of need for mental health services is essential to improving access to appropriate care and increasing treatment prevalence to promote evidence-based practice and improved outcomes.

Specific Aims

This study had two specific aims. The first specific aim was to gather data about the characteristics of NPs, their practice settings, and their level of interaction with pediatric patients with ND in NC. The second specific aim was to identify areas of knowledge, information, and skills needed by NPs caring for children with ND and to estimate the current level of interest regarding knowledge enhancement in the pediatric, family, and psychiatric/mental health NPs in the state.

Methods

Instrument

The instrument for this study was an online survey developed for the study. The survey consisted of 6 demographic questions, 5 perceived knowledge questions, 11 questions regarding current level of interaction with the screening, diagnosis, and treatment of children and adolescents with potential or existing ND and/or behavioral concerns, 11 questions designed to assess knowledge about ND and management of patients with ND, and 1 question each about perceived barriers to optimal care, areas of interest in and preferred modalities of further education and training. The Institutional Review Board at the University of North Carolina at Chapel Hill determined that this study was exempt due to the anonymity of the survey participants.

Sample and Sampling Design

In order to obtain the broadest response, a list of email addresses was requested from the NC Board of Nursing for all Pediatric, Family, and Psychiatric Mental Health Nurse Practitioners in their database. Two thousand three hundred and forty-six email addresses were obtained, 313 for Pediatric Nurse Practitioners (PNPs), 1929 for Family Nurse Practitioners (FNPs), and 104 for Psychiatric Mental Health Nurse Practitioners (PMHNPs). In order to capture the maximum number of NPs who work with pediatric patients with ND, all 2,346 NPs were invited to participate. One of the initial questions on the survey was, "In your practice environment, do you care for children and adolescents?" Participants who answered "no" to this question were informed they did not need to complete the remainder of the survey and were not included. All NPs who answered "yes" to this question were included in the sample.

Data Collection Procedures

An invitational email was sent that introduced the investigators, defined the study and its purpose, and included the link for accessing the online survey through the survey engine, Survey Monkey. A reminder email was sent 10 days following the initial invitation and then a third and final reminder was sent 10 days after the second invitation. Data collection closed 10 days following the final invitation. The survey was open for a total of 30 days.

Statistical analysis

Descriptive statistics including frequencies for categorical variables and means for continuous variables were generated. A total correct knowledge score was generated for the 11 questions regarding knowledge about ND and the management of patients with ND. One-way ANOVA and t-test were used to compare across respondent characteristics. When the F tests were significant, post hoc analyses using Duncan's multiple range tests were conducted to determine mean differences. Each correct knowledge score was compared to selected categorical variables using Chi-squared or Fisher's exact tests. Statistical analyses were performed using SAS version 9.2 (SAS Institute Inc. Cary, NC) and p-values less than 0.05 were considered significant.

Results

A total of 414 NPs from NC began the survey. Of these, 309 (75%) completed the survey and comprise the final sample. Participants ranged from 21 to greater than 61 years of age; years of experience as an NP ranged from less than one year to over 30 years. The majority of the NPs practiced in primary care/medical home environments distributed fairly equally across urban, suburban and rural settings. Of the 309 NPs who completed the survey, seven were dual certified as FNP and PMHNPs, six as PNP and FNPs, and one as a PNP and PMHNP. Ten of the respondents had completed their Doctorate of Nursing Practice (DNP) and seven had completed their PhD in Nursing. Of the respondents 25.9% reported no prior ND education. Of the remaining 74.1% of respondents, they reported their exposure to ND education (multiple options could be chosen) included CME/CE courses 59.6%, seminars/workshops 28.5%, graduate coursework 21.7%, mini-fellowships 1.3%, fellowships 0.7%.

The data on the top six screening tools utilized by NC NPs from greatest to least included Ages and Stages (ASQ) 44.9%, Modified Checklist for Autism in Toddlers (M-CHAT) 33.3%, Denver Developmental Screening Test (DDST) 24.6%, Parental Evaluation of Developmental Status (PEDS) 23.3%, Ages and Stages: Social/Emotional (ASQ:SE) 16.8%, Autism Spectrum Screening Questionnaire (ASSQ) 12.9%, and Behavior Assessment System for Children (BASC-2) 10%. The guidelines utilized by the respondents included the Autism Spectrum Disorders (ASD) guidelines (34.3%), the Attention Deficit Disorder (ADD) guidelines (54.37%), and guidelines for Attention Deficit Hyperactivity Disorder (ADHD) (63.75%).

To address specific aim 2, respondents were asked to rate their current understanding of ND, as well as, knowledge of screening tools, pharmacological interventions, behavioral treatments and interventions, and familiarity with community-based support and resources. Respondents rated their knowledge as excellent, very good, good, fair or poor. Findings are presented in Figure 1. Fully half (50.65%) reported a fair or poor knowledge of pharmacological interventions for persons with ND. In contrast, 64.14% report prescribing pharmacological therapies in the last year; 10.53% reported prescribing these therapies to ten or more patients, and 19.74% reported prescribing these therapies to 20 or more patients a year. As regards behavioral treatments and interventions for children and adolescents with ND, 54.3% rated their knowledge at fair or poor but 52% reported prescribing behavioral therapies; 9% to more than ten patients a year and 12.67% to more than 20 patients a year.

Statistically significant differences in perceived competencies were identified by the type of certification, (PNP, FNP, PMHNP). Participants reported significantly different perceived competencies in the following areas: current understanding of ND ($p < .001$, Fisher's exact test), knowledge of developmental screening tools ($p = .001$), familiarity with community-based support and resources ($p = .006$), and knowledge of behavioral treatments and interventions for persons with ND ($p = .035$). In general, greater perceived competencies (i.e., excellent to good understanding) were reported among those who indicated that they had dual certification, followed by PNPs.

A knowledge score was calculated for each respondent based on the number of correct answers to the 11 true/false knowledge questions. Cronbach's α for this knowledge scale was acceptable at 0.71. The respondents' perceived knowledge scores were found to be related to the mean of the respondents' scores to the 11 knowledge questions. The NPs who rated their current understanding of ND as excellent, very good, or good had higher total mean knowledge scores than those who felt their understanding was fair or poor ($p = .002$). In addition, NPs who rated their knowledge of developmental screening tools and familiarity with community-based support and resources for children and adolescents with possible or diagnosed ND as excellent, very good, or good had a greater total mean knowledge score than those who felt they had fair or poor knowledge ($p = .009$, $p = < .001$ respectively). Those who perceived their knowledge of pharmacological interventions, and behavioral treatments and interventions for persons with ND as excellent, very good, or good also had a greater total mean knowledge score than those who indicated fair or poor knowledge ($p = .015$, $p = .019$ respectively).

Chi-square tests were conducted to examine relationships between each correct true/false question about knowledge and management practices regarding ND and the selected participants' characteristics. Significant relationships were found between the question, "The AAP recommends developmental surveillance at every well-child visit and developmental testing at certain ages" and (a) type of practice environment, (b) the number of referrals they made for a specialist related to ND ($p = .005$, Fisher's exact test), (c) the number of initial consultations or screenings they completed, $X^2(3, N = 306) = 8.131$, $p = .043$, (d) perceived knowledge of developmental screening tools, (e) perceived familiarity with community-based support and resources, and (f) whether or not the participant's practice setting has a referral system. That is, the extent to which NPs reported the correct answer was different depending on the type of practice environment in which they were employed (i.e., primary care/medical home, community-based referral/specialty, medical center referral/specialty, private sector, public sector, school system) ($p = .001$, Fisher's exact test). In particular, those who perceived excellent, very good, or good knowledge of developmental screening tools, $X^2(1, N = 307) = 10.138$, $p = .002$, and familiarity with community-based support and resources, $X^2(1, N = 307) = 9.226$, $p = .002$, answered more correctly than those who indicated a fair or poor knowledge and familiarity. NPs who reported that their practice setting had a referral system answered more correctly than those who did not have such a system, $X^2(2, N = 306) = 6.043$, $p = .049$.

The extent to which NPs selected the correct answer for the question, "Standardized Developmental Testing with validated screening tools is mandated and necessary for sensitivity in accurately determining the presence of intellectual/developmental problems in children" was significantly different depending on the type of practice environment in which they were employed ($p = .010$, Fisher's exact test). In addition, those who had 5–14 years of experience as NPs were more likely to answer the question correctly than those who worked less than 5 or greater than 14 years, $X^2(2, N = 302) = 9.914$, $p = .007$.

With regard to the question, "Developmental disabilities include intellectual disabilities as well as other physical limitations and disabilities," the extent to which NPs reported the correct answer was significantly associated with their practice environment ($p = .019$,

Fisher's exact test), and those who rated their familiarity with community-based support and resources as excellent, very good, or good were more likely to answer correctly than those who felt their familiarity was fair or poor, $X^2(1, N = 301) = 5.160, p = .023$. In addition, familiarity with community-based support and resources was significantly associated with the question, "Children and adolescents with ND are at higher risk for hypothyroidism, osteoporosis, seizure disorders, gastric disorders, respiratory infections, and premature aging" in that NPs who reported excellent, very good, or good familiarity were more likely to answer the question correctly than those who reported their familiarity was fair or poor, $X^2(1, N = 300) = 4.600, p = .032$.

Finally, the question, "Only 30–40% of parents will volunteer concerns about their child's development without prompting" was significantly related to the characteristic (i.e., the type of practice environment, $p = .028$, Fisher's exact test) and perceived competencies of NPs (i.e., current understanding of ND, $X^2(1, N = 301) = 16.085, p < .001$, knowledge of developmental screening tools, $X^2(1, N = 301) = 7.943, p = .005$, familiarity with community-based support and resources, $X^2(1, N = 301) = 6.730, p = .010$, knowledge of pharmacological interventions, $X^2(1, N = 300) = 5.567, p = .018$, and knowledge of behavioral treatment interventions for persons with ND, $X^2(1, N = 301) = 4.575, p = .032$). That is, NPs who indicated excellent, very good, or good competencies in knowledge and management practices regarding ND were more likely to answer the question correctly than those who reported fair or poor competencies.

The respondents were asked to identify what if any barriers impacted their ability to screen, diagnose, and manage care for children and adolescents with potential or existing ND and associated behavioral concerns. The barrier which was most often identified by respondents was their knowledge of ND and comorbid disorders and sequelae (42.72%). Other identified barriers are included in Figure 2.

A list of possible areas of interest for future education was also included in the survey. Participants showed interest in multiple educational mechanisms to expand knowledge and care management skills. Both developmental assessment and pharmacological therapies were topics of highest interest for further education (52.75% of respondents).

Discussion

Nurse Practitioners in NC provide care to pediatric patients in a variety of settings and environments. Over 75% of the NPs who participated in this study provided some level of care for patients with potential or existing ND, 64% prescribed pharmacological therapies, and 52% prescribed behavioral therapies. The implications of these findings on the potential impact of education, practice, and research is far reaching as improvements in any and all of these areas has the ability to impact the knowledge and care management skills of NPs who actively work with this population.

Despite the significant variety of characteristics of NPs in NC described by the results of this study, there were important similarities with regard to their comfort level with the knowledge and care management skills required to effectively care for pediatric patients

with potential or existing ND. More than 50% recognized deficiencies in their understanding related to knowledge of ND and comorbid disorders and sequelae. Almost 50% noted barriers to the care they provide for this population related to lack of familiarity with community-based support and resources, lack of familiarity with appropriate or available specialists/consults/referrals, behavioral care management practices, pharmacological care management practices, and proper coding for appropriate level of reimbursement for services. The respondents identified significant barriers to identifying and providing care for children with intellectual/developmental concerns. These findings suggest that further improvement in our ability to assess, diagnose, and manage ND still present challenges for primary care providers.

The NPs in the study appeared to have an accurate understanding of their own knowledge and skills related to caring for children and adolescents with ND. That is, there was a significant relationship between self-ratings and assessed knowledge scores. With the existing knowledge gaps and recognized barriers to providing care it is reasonable that discomfort with caring for this population exists among NPs. Further, an important indicator for planning continuing education, nearly 70% of all the respondents expressed an interest in improving their knowledge and skills related to ND in children and adolescents.

Implications for education

The implications for education are multi-faceted and should include practicing and student NPs. Implications include building a framework for education, determining sequence, depth, and breadth of relevant evidence based information to share, designing and implementing educational resources/curricula for multiple modalities, and informing practicing professionals and NP programs about new educational opportunities.

The ability to reach out with educational opportunities to NPs with modalities that are convenient and preferred is essential. Over 60% of the study respondents had completed some continuing education, mostly in the form of CMEs related to ND. The preferred modalities for this sample were self-paced modules followed by written materials, lecture/traditional workshops, and then on-line workshops. Creating adaptable educational opportunities that can be disseminated through a number of different modalities should prove to be most effective and could be included in master's level curricula as well. Addressing the educational needs of NPs now can help address the needs of the growing population of children and adolescents with ND. Unless we assist health care providers to become comfortable and proficient with their knowledge and care management skills, the quality of care obstacles that are found in the current system will likely persist. In 2002, the American Board of Pediatrics recognized the need for evidence based treatments of mental health and associated behavioral needs and created specialty training for pediatricians in Developmental and Behavioral Pediatrics. Since this specialty was created, only 720 physicians have completed the training to obtain this certification.⁸ In 2011, the Pediatric Nursing Certification Board (PNCB) launched a new certification, the Pediatric Primary Care Mental Health Specialist Certification (PMHS), for PNPs and FNPs as well as the clinical nurse specialist.⁹ This certification requires a minimum of 1,000 APRN primary care clinical hours in behavioral/mental health as well as pharmacology contact hours and

continuing education in mental health content. As of 2014, 307 people have received a PMHS certification nationally.⁹

This study found that 52.75% of NC NP respondents were interested in increasing their knowledge and care management skill set. As NPs become more comfortable with their knowledge and care management skills there is reason to believe that at the practice level many children and adolescents will reap the benefits.

Implications for practice

The study results indicate both a need for further knowledge regarding this population and continued support and clinical education regarding their management. The study results indicate the desire of NPs in the state to provide effective screening, appropriate diagnoses, referrals, and evidence based therapies to their patients. This study showed that there are many PNPs and PMHNPs in the state who are screening, diagnosing, referring and treating patients with ND. Over 75% of the respondents reported providing care for a child or adolescent with ND, almost 30% reported doing the initial consult for a child with a possible ND or behavioral concern, and 65% prescribed medications to treat this population over the last year. The lower response from FNPs may mean that this population is less likely to be part of their practice.

As the number of children and adolescents with ND and associated behavioral concerns grow, the number of healthcare interactions with NPs are likely to grow. NPs can play a significant role in efforts to improve outcomes for this population. Further, the overlaps between primary care and specialty care for children and adolescents with ND and associated behavioral concerns are many. Evidence-based practice in primary care settings involves a great deal of preventative surveillance, screening, and/or diagnosis, referrals, and treatment for attention and behavioral disorders, as well as autism spectrum disorders. Findings from this study provide evidence that many NPs have knowledge deficits regarding the surveillance, screening, diagnosis, referral, and care management of children and adolescents with ND and associated behavioral concerns. Furthermore, almost half of the respondents identified barriers to providing care for this population and slightly over half expressed interest in obtaining further education and training to improve their knowledge and care management practices. Moreover, NPs who provide care in primary care pediatric offices are ideal persons to receive this training, as surveillance for ND and identification of ND and behavioral concerns should be an integral part of providing primary care to all children and adolescents. Thus the most logical environments for the implementation of measures to improve knowledge and care management practices are those environments where primary care is provided. This sentiment was also recently echoed in Current Opinion Pediatrics which reported that pediatric settings are the optimal place for screening, detecting and addressing mental/behavioral health concerns because up to 50% of all pediatric visits address these areas of concern.⁹

Implications for research

The implications for further research indicated by this study include the need to determine content, staging, and type of educational curricula that should be created, and how such

curricula could be adapted to both further the knowledge and skills of currently practicing NPs as well as assist student NPs in the acquisition of such knowledge and skills. Further, research may need to be done which determines at which point the scope of practice needs to move from that of a primary care provider to a specialty care provider and what types of communication and collaboration will be needed to continue to promote an effective primary care and specialty care relationship while fostering the best access and outcomes for the patients.

Study limitations

There were several limitations to this study. This study did not restrict the invited participants to only those NPs who were providing care to children and adolescents. Therefore, the PMHNPs and FNPs who provide care to adult only populations would not have participated, yielding an apparently low response rate for these two groups. Of greater import, this study reports results from a convenience sample; thus PNP, FNPs and PMHNPs in NC with an interest in children with ND are most likely to have responded. This may overstate both knowledge of respondents and need for education. The study was solely quantitative and online. Future studies that include both qualitative and quantitative components could reveal important issues related to aspects of knowledge and care not included in the current study. Another limitation was that no individual contact information regarding a respondent's desire to be included in future related studies was ascertained.

Conclusions

The findings from this study support the provision of further education and training for NPs caring for children and adolescents with ND and associated behavioral concerns in NC. These efforts should support an improved adherence to guidelines, the use of appropriate screening tools, the earlier diagnosis of ND and associated behavioral concerns, and better understanding of ND and its sequelae and comorbid conditions. Further, the improved knowledge with ND patient care will support better communication and collaboration between the NPs providing primary care and the healthcare specialists and resources in the community. Ultimately increasing NPs comfort and familiarity with evidence-based practices will create improved access to care, improved care management, and improved ND patient outcomes.

In March 2014, provisions to the Federal Excellence in Mental Health Act were made that will invest one billion dollars into the behavioral health system. On October 19, 2015 the Substance Abuse and Mental Health Services announced the first 24 states to receive funding. NC was a recipient of this funding for planning grants for Certified Community Behavioral Clinics.¹⁰ These efforts further signal a need and a readiness to improve access and care for the unique needs of this population.

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References

1. Doody, Catriona M., Doody, Owen. Health promotion for people with intellectual disability and obesity. 2012
2. Smith, M., Escude, C. Intellectual and developmental disabilities. 2015. Retrieved from: <http://www.clinicaladvisor.com/intellectual-and-developmental-disabilities/printarticle/395169/>
3. North Carolina Institute of Medicine (NCIOM). Early Childhood Mental Health Task Force DRAFT Recommendations. 2011. Retrieved from: http://www.nciom.org/wp-content/uploads/2011/06/ECMH_Potential-Recs-10-20-11.pdf
4. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5. Washington, DC: APA; 2013.
5. Boyle C, Boulet S, Schieve L, Cohen R, Blumberg S, Yeargin-Allsopp M, Kogan M. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*. 2011; 127:1034–1042. [PubMed: 21606152]
6. Center for Disease Control. Developmental disabilities. 2015. Retrieved from <http://www.cdc.gov/ncbddd/dd/dd1.htm>
7. Weitzman C, Wegner L. Promoting Optimal Development: Screening for Behavioral and Emotional Problems. *American Academy of Pediatrics*. 2015; 135(2):384–395. [PubMed: 25624375]
8. American Board of Pediatrics. Workforce and Research. 2010. Retrieved on March 26, 2012, <https://www.abp.org/abpwebsite/stats/wrkfrc/workforce08.pdf>
9. Pediatric Nursing Certification Board. [Accessed April 2016] Pediatric Nursing Certification Board. 2015. <https://www.prometric.com/en-us/clients/pncb>
10. [Accessed April 2016] HHS awards up to \$22.9 million in Planning Grants for Certified Community Behavioral Health Clinics. tiffany.bridge. <http://www.samhsa.gov/newsroom/press-announcements/201510191200>

Highlights

- NC NP's have varied educational history and experience.
- NC NP's reports poor to fair understanding of many aspects of I/DD care management.
- NC NP's report the desire to learn about improving screening and care for I/DD.

Figure 1.
NC NP Self-Assessed Knowledge Ratings

Figure 2.
NP Reported Barriers to Care of ND (% of Respondents)