

Neonatal Abstinence Syndrome and its Specifics at Temporary Foster Care Institution in the Czech Republic: Study Protocol

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INTRODUCTION: Neonatal Abstinence Syndrome (NAS) is a condition unique to a newborn that results from the abrupt cessation of chronic intrauterine drug exposure following birth. Slightly persistent, late onset, or slowly fading-out symptoms' manifestation may take weeks or months. In case the infant is not kept in the biological family, one possible subsequent placement after discharge from hospital in the Czech Republic is a Temporary Foster Care Institution called Pěstounská péče na přechodnou dobu (TFCI). It is unclear what knowledge, education, and experience TFCI caregivers have in NAS infant care so far. The monitoring of persistent symptoms of NAS in the specific environment of foster care has not been realized yet. This is the first time the Finnegan Neonatal Abstinence Scoring Tool (FNAST) tool will be used for NAS symptoms monitoring in the TFCI environment. **METHODS:** Preliminary study of NAS incidence from Czech national health registers will be

followed by a main study divided into two parts. First part is designed as a cross-sectional questionnaire survey investigating TFCI caregivers' awareness, knowledge, and experience with NAS infants in their practice. The second part of the study is designed as an observational longitudinal survey on a set of respondents: TFCI caregivers exclusively giving care to NAS diagnosed infants following late-onset / late fading out NAS symptoms using the FNAST scoring system. **DISCUSSION:** Based on the results from the longitudinal survey, it should be clarified whether the late symptoms of NAS persist and in what intensity in the TFCI environment and whether the FNAST tool is suitable for their monitoring, or whether it needs to be modified for the purposes of fostering practice. It is expected to not only help to understand the symptoms of NAS but also contribute to facilitating communication between TFCI caregivers and health care professionals (HCP) throughout the trajectory of providing care for NAS diagnosed infants.

Keywords | Neonatal Abstinence Syndrome (NAS) – Finnegan Neonatal Abstinence Scoring Tool (FNAST) – Pěstounská Péče na Přechodnou Dobu – Temporary Foster Care Institution (TFCI) – Oddělení Sociálně Právní Ochrany Děti – Authority of Social-Legal Protection of Children (ASLPC)

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1 INTRODUCTION

One of the significant public health negative impacts of the use of psychotropic substances is their abuse by women during pregnancy. Some psychotropic addictive substances, especially those with low molecular weight and a lipophilic nature, pass into the bloodstream of the fetus through the placental barrier (van Hoogdalem et al., 2021, Malek et al., 2009, Feghali et al., 2015). Exposure to psychotropic substances in the prenatal stage and their sudden withdrawal at birth leads to the development of Neonatal Abstinence Syndrome (NAS) in the newborn. In ICD-10, the International Classification of Diseases, 10th Revision, NAS is classified by international code P96.1 and is characterized as a multisystem disorder resulting from chronic in-utero exposure and its abrupt termination at birth (Jilani et al., 2021, Kocherlakota et al., 2014).

Clinically important NAS most commonly results from intrauterine opioid exposure (Gomez-Pomar et al., 2018). NAS clinical features categorize into central nervous system, autonomic, respiratory, and gastrointestinal system disturbances (Anbalagan et al., 2022). Optimal management of an infant with NAS includes hospitalization with non-pharmacological care and/or pharmacological treatment protocol (Grossman et al., 2019, Mangat et al., 2019). Since the mid-1970s, the Finnegan Neonatal Abstinence Scoring Tool (FNAOST) screening has been used worldwide for diagnosis, initiation of treatment, monitoring, and evaluation of NAS symptoms intensity. Dr. Loretta Finnegan and her team developed an unprecedented scoring system with a clinimetric approach for a total of 21 monitored NAS circuits after prenatal opioid exposure (Finnegan et al., 1975). This system is based on the subjective qualitative monitoring of individual symptoms at precise time intervals of 2–4 hours. The occurrence and intensity of the given symptoms are monitored on a scale of 1–8 and 1–12, respectively. As soon as the intensity of the symptom reaches its maximum, i.e., above a score of 8, or above 12 in a given time interval, pharmacological treatment is deployed. The onset of NAS can be delayed in some infants, beginning at 5 to 7 days of age, which is typically after hospital discharge for uncomplicated term infants. Thus, there is a risk for adverse outcomes, including hospital readmission (Kandall et al., 1974, Maalouf et al., 2018).

In case the infant is not kept in the biological family, one possible subsequent placement after discharge from hospital is a Temporary Foster Care Institution called *Pěstounská péče na přechodnou dobu* (TFCI) in the Czech Republic. Thus, the symptoms may occur or persist in less or more important intensity once the infant is subsequently under foster care. The symptoms caused by dysregulations in one or more of the domains of central nervous system, autonomic, respiratory, and gastrointestinal system disturbances can interfere with essential neonatal functions such as feeding, sleeping, growth, emotional regulation, or social interaction (Velez et al., 2008). It is not clear yet to what extent TFCI caregivers encounter these dysfunctions linked to late onset or slowly fading out symptoms. Until now, in the Czech Republic, a system for monitoring persistent symptoms of NAS in the specific environment of foster care has not been established, and there is no tool that would help foster parents evaluate the condition of the infant and assist in communication with health care professionals (HCP).

2 STUDY BACKGROUND

This study is built upon two pillars: Firstly, TFCI in the Czech Republic, and secondly, the eventual NAS late-onsetting or late-fading-out symptoms in infants placed in this TFCI foster care environment. To properly substantiate the presence of late-onsetting or late-fading-out symptoms' intensity once the infant is placed in foster care, it is necessary to identify its prevalence, TFCI caregivers' knowledge and education about NAS disease, and finally, establish a tool allowing measurement all these factors.

Regarding the institution of TFCI, from June 1, 2006, the legal regulation of foster care in the Czech Republic was supplemented by a new special regulation (Paragraph 45a, Sect 2 of the Family Law Act, 94/1963), adopted with the aim of emphasizing the need for short-term foster care in clearly defined situations. Thus, TFCI was introduced as an alternative to placing a child in an institution. Additionally, the Czech Republic Senate approved an amendment to Act No. 359/1999 on the social and legal protection of children enacting an age limit of 3 years which will take place from January 1, 2025. It was approved that under this age, it will no longer be possible to place infants in any institutional care but TFCI, except for infants with severe disabilities and sibling groups. After this date, TFCI, particularly of infants, will gain even more importance.

In the context of NAS, TFCI caregivers' preparation for a significant change in the organizational arrangement in 2025 requires a so-far non-existent mapping of the current situation of their NAS knowledge, experience, and needs. Thus, mapping NAS late-onsetting and late-fading-out symptoms' intensity under TFCI care and finally introducing NAS communication tool for TFCI caregivers and HCP is a response to the current situation, in which these components are so far missing. Understanding and responding to persisting NAS symptoms manifestations may help to promote the infant's self-organization and self-regulation (Als et al., 2005).

Based on a worldwide successful use of FNAOST in hospital conditions by HCP (Hudak et al., 2012), it is believed that the implementation of this specific scoring system in TFCI caregivers' competences and practice will not only help identify and understand late-onsetting or persistent NAS symptoms but also facilitate communication between TFCI caregivers and HCP. Scoring may need to be adjusted for older infants to reflect their progress developmentally. For example, the sleep item may be eliminated to allow the older infant to sleep for shorter periods between feedings, so it does not "count against" the infant and result in a higher score than appropriate (Jansson et al., 2019).

3 PROJECT OBJECTIVES

3.1 Research questions

1. What is the incidence of NAS in the Czech Republic, and what are other medical factors associated with diagnosis P96.1?
2. What is the level of TFCI caregivers' knowledge, experience, and education regarding NAS infant care?

3. Is the FNAST applicable in TFCI caregivers' practice? Is there a need for its modification reflecting infant age and TFCI caregivers' practice?

3.2 Research objectives

The aim of this project is to describe NAS incidence and its other medical factors in the Czech Republic as a contextual frame for verifying whether and to what extent NAS symptoms persist in the TFCI foster care environment. Another goal is to verify whether the FNAST can be implemented in TFCI practice as a tool for optimizing not only knowledge and education regarding NAS but also as a basis for defining specific needs and difficulties in the care for individuals with persistent NAS symptoms. Finally, the aim is to recommend a still missing communication tool for TFCI and the professional health public, thus facilitate this specific care.

1. To respond to research question No.1, a preliminary study of NAS incidence and associated medical factors based on Czech national health registers administered by the Institute of Health Information and Statistics of the Czech Republic (IHIS), specifically the National Newborn Registry, is provided as Sub-study 1.
2. Research question No.2 is elaborated by a study determining TFCI caregivers' practice-based awareness and knowledge of NAS infant care - Sub-study 2.
3. To respond to research question No.3, a study using FNAST by TFCI caregivers exclusively giving care to NAS diagnosed infants (their medical record includes diagnoses of NAS or diagnosis P96.1) to verify the feasibility of identifying late-onsetting or late-fading-out NAS symptoms under TFCI foster care conditions and point out and define foster caregivers' specific needs and difficulties facing NAS infant care using FNAST - Sub-study 3.

4 METHODS AND ANALYSES

4.1 Design

Sub-study 1: Content analysis of NAS incidence and related health factors

Objective: To conduct a content analysis of NAS incidence and related health factors using data from the Czech National Health Registers managed by the Institute of Health Information and Statistics (IHIS).

Description: This sub-study serves as a preliminary part of the study, providing a contextual framework.

Sub-study 2: Cross-sectional questionnaire survey for TFCI caregivers in the Czech Republic

Objective: To explore TFCI caregivers' current practical knowledge and experience in providing care to infants with NAS.

Questionnaire structure:

- Two sets of questions: one for caregivers without NAS experience and another for those with NAS experience.
- Six socio-demographic questions and seven theoretical knowledge and awareness questions for caregivers without NAS experience.
- For caregivers with NAS experience, questions cover aspects like drug substances abused, hospitalization details, NAS symptoms, and caregiver techniques for symptom handling.

Sub-study 3: Observational longitudinal survey on TFCI caregivers exclusively giving care to NAS diagnosed infants

Objective: To observe and document late-onsetting/late-fading-out NAS symptoms in TFCI caregivers exclusively giving care to NAS diagnosed infants, using the FNAST tool.

Method:

- FNAST questionnaire in the form of an Excel table containing 21 NAS symptoms.
- Scoring principle involves subjective evaluation of symptoms on a 0–8 scale at regular intervals of 3 hours.
- Monitoring and scoring will occur from the time of infant admission to care until symptoms disappear.
- Educational material will be provided to assess caregivers' ability for subjective qualitative observation and quantitative scoring.

Overall study aim:

- To describe NAS incidence and related health factors in the Czech Republic.
- To verify the applicability of FNAST in TFCI practice for understanding and managing NAS symptoms.
- To recommend a communication tool for TFCI and health-care professionals, facilitating specific care for infants with NAS.

The research study consists of three parts:

Sub-study 1: Content analysis of NAS incidence and related health factors, data from the Czech National Health Registers managed by the Institute of Health Information and Statistics (IHIS), will be processed as a preliminary part of the study providing a contextual framework.

It will be followed by the Sub-study 2, designed as cross-sectional questionnaire survey addressed to all TFCI caregivers in the Czech Republic. The Sub-study 2 seeks to explore the TFCI caregivers' current practical knowledge and experience in providing care to infants with NAS since they began working in the field

of foster care givers institution. The questionnaire contains two sets of questions, one set for those who hadn't have any previous experience with NAS and one set of questions for those who had have experience with NAS such as given care either to diagnosed or to not diagnosed but suspected NAS infants.

There is six socio-demographic questions and seven questions concerning theoretical knowledge and awareness about NAS for those TFCI caregivers without NAS experience.

TFCI caregivers with experience of NAS can respond to four sets of questions in total, two sets for an infant diagnosed with NAS and two sets for an infant with NAS symptoms manifestation but not diagnosed. Each set of questions is divided into three parts:

1. Six questions concerning TFCI caregivers' sociodemographic factors and their knowledge and awareness of NAS disease.
2. Seven questions such as infant's mother drug substances abused, length of infant hospitalization before admission to TFCI, length of infant hospitalization during stay at TFCI, infant's outpatient medication, which of 21 NAS symptoms was manifested eventually.
3. 21 questions corresponding to length of 21 NAS symptoms manifestation linked to specific technique of TFCI caregivers handling the symptoms and source of TFCI caregivers' knowledge of this technique.

Sub-study 3 is designed as an observational longitudinal survey on set of respondents TFCI exclusively giving care to NAS diagnosed infants (their medical record includes the established diagnosis of NAS, or the diagnostic code P96.1). Late-onsetting/late fading out NAS symptoms expression will be collected using FNAST tool. FNAST questionnaire in form of an excel table contains 21 NAS symptoms. A prerequisite for this survey is monitoring and responding throughout the care period at regular intervals. The scoring principle consists in the subjective evaluation of 21 defined NAS symptoms with the appropriate score according to the subjective evaluation of the intensity of the given symptom. Late onset and late fading intensity are scored in 0 - 8 scale in regular intervals of 3 h. The scoring will take place from the time the infant is taken into care until the symptoms disappear. To assess the respondent's ability of subjective qualitative observation and quantitative scoring, the FNAST will be supplemented by educational material concerning description of manifestation of all symptoms.

4.2 Data source

In Sub-study 1, data collection will provide NAS incidence and medical factors linked to NAS as a preliminary context base based on Czech national health registers administered by the Institute of Health Information and Statistics of the Czech Republic, specifically the National Newborn Registry.

The Sub-study 2, the cross-sectional questionnaire survey data collection, is addressed to all TFCI in the Czech Republic. The method of obtaining the respondent sample is non-random

opportunity sampling (non-probability convenient sampling), or self-nomination, when respondents nominate themselves to participate in the research.

The Sub-study 3, the observational longitudinal survey data collection source, includes exclusively TFCI giving care to NAS diagnosed infants. Respondents in Sub-studies 2 and 3 will be approached through two institutions, the Authority for Social and Legal Protection of Children (Orgán sociálně-právní ochrany dětí, ASLPC) departments of all regional councils of the Czech Republic, and the Professional Association of Foster Parents (Profesní sdružení přechodných pěstounů z.s., PAFP). The method of obtaining the respondent sample is non-random opportunity sampling (non-probability convenient sampling), or self-nomination, when respondents nominate themselves to participate in the research.

4.3 Study population and size

The population of Sub-study 1 are 1,285 infants diagnosed with NAS registered in the National Newborn Registry of Czech national health registers from 1994 to 2021. There were 2,901,205 total live births between 1994 and 2021 in the Czech Republic.

The population of Sub-study 2 consists of foster caregivers recruited from all TFCI in the Czech Republic. There are approximately 700 TFCI caregivers registered in 2022.

The sample of Sub-study 3 includes exclusively TFCI caregivers of NAS diagnosed infants in 2023–2024.

4.4 Analysis strategy and statistics tool

The descriptive analysis of Sub-study 1 data from Czech national health registers, administered by the Institute of Health Information and Statistics of the Czech Republic, specifically the National Newborn Registry, will include basic calculations (averages and medians) of relevant variables such as NAS incidence, co-morbidity, length of hospitalization, and type of medication as a contextual framework of the situation in the Czech Republic.

Sub-study 2 data, the cross-sectional survey, allows for not only providing a descriptive analysis of variables such as TFCI caregivers' practice-based NAS disease symptom knowledge, previous experience of giving care to NAS infants, or source of NAS disease education but also to determining associations between each specific NAS symptom manifestation and care resolution knowledge. This data provides an overview of the occurrence of NAS under foster care by TFCI and highlights the specific needs for caring for NAS infants.

The data from Sub-study 3, the observational longitudinal survey using FNAST, allow for more sophisticated analyses such as multiple regressions and correlations of associated variables, including prospective length of each of NAS symptom manifestation, their co-manifestation, and intensity. Finally, inferential statistics of these data will provide analyses of relationships between these variables.

All data statistical analyses are performed on free and open statistical platform called Jamovi.

5 STRENGTHS AND LIMITATIONS

1. Successfully managed TFCI volunteers' recruitment can influence the convenient sample size of respondents. Therefore, their acquisition is handled by cooperation with Profesní sdružení pěstounů na přechodnou dobu z.s. and through TFCI registers at ASLPC departments of all regional councils of the Czech Republic.
2. Observational longitudinal survey using FNAST needs motivation of TFCI caregivers, computer skills, NAS symptom knowledge. There may be a tendency that respondents are more inclined to answer the questionnaire if they are more familiar with some of NAS symptom manifestations. This situation would inflate the incidence results found in our sample. As FNAST is used purely by HCP, there is a need to provide respondents with sufficient training, and quality control should be maintained throughout the study. Within the questionnaire, the educational material is included according to established guidelines. The loss of follow-up is handled by continuous support of education and supervision.
3. Longitudinal design has usually dropout of participants over time. It would be compensated by continuous recruitment of foster caregivers with recently admitted NAS diagnosed infants.
4. The sample size is also limited by the number of captured NAS diagnosed infants in 2023–2024.

5.1 Ethics and dissemination

The study protocol was approved by the ethics committee of the National Monitoring Centre for Drugs and Drug Addictions of the Czech Republic under reference number EKNMS-2/2023.

6 CONCLUSION

In recent decades, research supports the notion that a child's relational experiences with the environment and caregivers strongly influence neuroanatomical and physiological development during the first years (Velez et al., 2008). Therefore, the establishment of TFCI responds to the need for intensive supportive management of infants under 3 years of age in the Czech Republic.

However, appropriate supportive care of the in-utero drug-exposed infant requires accurate identification of persistent expressions of NAS, triggers of the symptoms, and individualized

plan for care. TFCI caregivers' awareness of different NAS symptom manifestations, behavioral states, and the importance of recognizing the child's ability to regulate them are essential.

The presence of late-onsetting or persisting NAS symptoms occurring in the specific foster care environment constitute a subject of drug-related harm reduction in the field of addicology. The manifestation of 21 NAS symptoms and their intensity recorded by TFCI using FNAST should provide a consistent description of the situation. These findings should lead to pointing out and defining TFCI caregivers' specific needs and difficulties facing NAS infant car.

Based on the findings of Sub-study 3, the FNAST could be further refined for TFCI practice through ongoing optimization and incorporating feedback from TFCI caregivers. This adaptation of the specific scoring system to align with TFCI caregivers' competences and practices is anticipated to yield a customized tool. This tool is envisioned not only to enhance understanding of NAS symptoms but also to play a pivotal role in fostering effective communication between TFCI caregivers and healthcare professionals throughout the continuum of caring for infants with NAS.

REFERENCES

- Als, H., Butler, S., Kosta, S., & McNulty, G. (2005). The assessment of preterm infants' behavior (APIB): Furthering the understanding and measurement of neurodevelopmental competence in preterm and full-term infants. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(1), 94–102. <https://doi.org/10.1002/mrdd.20053>
- Anbalagan, S., & Mendez, M. D. (2023). *Neonatal Abstinence Syndrome*. StatPearls Publishing. <http://www.ncbi.nlm.nih.gov/books/NBK551498/>
- Feghali, M., Venkataramanan, R., & Caritis, S. (2015). Pharmacokinetics of drugs in pregnancy. *Seminars in Perinatology*, 39(7), 512–519. <https://doi.org/10.1053/j.semperi.2015.08.003>
- Finnegan, L. P., Connaughton, J. F., Jr, Kron, R. E., & Emich, J. P. (1975). Neonatal abstinence syndrome: Assessment and management. *Addictive Diseases*, 2(1-2), 141–158.
- Gomez-Pomar, E., & Finnegan, L. P. (2018). The epidemic of neonatal abstinence syndrome, historical references of its origins, assessment, and management. *Frontiers in Pediatrics*, 6, Article 33. <https://doi.org/10.3389/fped.2018.00033>
- Grossman, M., & Berkwitz, A. (2019). Neonatal abstinence syndrome. *Seminars in Perinatology*, 43(3), 173–186. <https://doi.org/10.1053/j.semperi.2019.01.007>
- van Hoogdalem, M. W., Wexelblatt, S. L., Akinbi, H. T., Vinks, A. A., & Mizuno, T. (2022). A review of pregnancy-induced changes in opioid pharmacokinetics, placental transfer, and fetal exposure: Towards fetomaternal physiologically-based pharmacokinetic modeling to improve the treatment of neonatal opioid withdrawal syndrome. *Pharmacology & Therapeutics*, 234, Article 108045. <https://doi.org/10.1016/j.pharmthera.2021.108045>
- Hudak, M. L., Tan, R. C., Committee on Drugs, Committee on Fetus and Newborn, & American Academy of Pediatrics. (2012). Neonatal drug withdrawal. *Pediatrics*, 129(2), e540–e560. <https://doi.org/10.1542/peds.2011-3212>
- Jansson, L. M., & Patrick, S. W. (2019). Neonatal abstinence syndrome. *Pediatric Clinics of North America*, 66(2), 353–367. <https://doi.org/10.1016/j.pcl.2018.12.006>
- Jilani, S. M., Jordan, C. J., Jansson, L. M., & Davis, J. M. (2021). Definitions of neonatal abstinence syndrome in clinical studies of mothers and infants: An expert literature review. *Journal of Perinatology*, 41(6), 1364–1371. <https://doi.org/10.1038/s41372-020-00893-8>
- Kandall, S. R., & Gartner, L. M. (1974). Late presentation of drug withdrawal symptoms in newborns. *American Journal of Diseases of Children*, 127(1), 58–61. <https://doi.org/10.1001/archpedi.1974.02110200060008>
- Kocherlakota P. (2014). Neonatal abstinence syndrome. *Pediatrics*, 134(2), e547–e561. <https://doi.org/10.1542/peds.2013-3524>
- Maalouf, F. I., Cooper, W. O., Slaughter, J. C., Dudley, J., & Patrick, S. W. (2018). Outpatient pharmacotherapy for neonatal abstinence syndrome. *Journal of Pediatrics*, 199, 151–157. <https://doi.org/10.1016/j.jpeds.2018.03.048>
- Malek, A., Obrist, C., Wenzinger, S., & von Mandach, U. (2009). The impact of cocaine and heroin on the placental transfer of methadone. *Reproductive Biology and Endocrinology*, 7, Article 61. <https://doi.org/10.1186/1477-7827-7-61>
- Mangat, A. K., Schmölzer, G. M., & Kraft, W. K. (2019). Pharmacological and non-pharmacological treatments for the Neonatal Abstinence Syndrome (NAS). *Seminars in Fetal & Neonatal Medicine*, 24(2), 133–141. <https://doi.org/10.1016/j.siny.2019.01.009>
- Velez, M., & Jansson, L. M. (2008). The opioid dependent mother and newborn dyad: Non-pharmacologic care. *Journal of Addiction Medicine*, 2(3), 113–120. <https://doi.org/10.1097/ADM.0b013e31817e6105>