

Neonatal Abstinence Syndrome:

How States Can Help Advance the Knowledge Base for Primary Prevention and Best Practices of Care





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I. Executive Summary

Over the last decade, there has been increasing public health, medical, and political attention paid to the parallel rise in two trends: an increase in the prevalence of prescription opioid abuse and an increase in the incidence of neonatal abstinence syndrome (NAS). There has been a significant increase in the prevalence of NAS, from 1.20 per 1,000 U.S. hospital births in 2000 to 3.39 per 1,000 U.S. hospital births in 2009.³

Prevention and intervention opportunities to avert or ameliorate the outcome of NAS can be considered along a continuum of care spanning timeframes in the mother and infant's life: the preconception period, during pregnancy, at birth, the postpartum or neonatal/infancy period, childhood, and beyond. There are several points when a woman or her family can be lost to follow-up, such as during the handoff between agencies or providers. State health agencies play a key role in linking various resources and providers by tracking substance-exposed infants through screening, assessment, and service delivery.⁴

Taking a public health approach to routine screening for unhealthy substance use in women at every healthcare visit can help increase the opportunities for primary prevention. States can support the American Congress of Obstetricians and Gynecologists' (ACOG) recommendation for universal substance use screening in early pregnancy in a variety of ways. State agencies, quality improvement efforts, and perinatal collaboratives can advance prenatal screenings as the expected standard of care for obstetric providers. State health agencies can ensure that Medicaid reimburses for substance abuse screening, support provider education and training, and streamline entry points for substance abuse treatment.

Although medication-assisted treatment is a centerpiece of managing opioid dependency in pregnancy, it is best applied as part of a comprehensive treatment program that includes obstetric care, counseling, and wrap-around services.² Methadone maintenance programs and office-based buprenorphine treatment offer two different models of service delivery. Family-centered care that is community-based is the ideal course to increase access and provide follow-up for the mother, infant, and family's evolving needs.

There are numerous perinatal approaches to screening for NAS in neonates and their subsequent management in birthing hospitals nationwide. Nearly all opioid-exposed infants will display some NAS symptoms, but only a subset of infants will need pharmacotherapy.⁵ Outlined in a 2012 American Academy of Pediatrics (AAP) policy statement, "Neonatal Drug Withdrawal," the AAP Committee on Drugs recommends scoring NAS symptoms using an appropriate tool to assist with therapeutic treatment decisions.⁸ Several tools are available for quantifying the severity of neonatal withdrawal signs, including the Lipsitz tool, Finnegan scoring system, Neonatal Withdrawal Inventory, and the Neonatal Narcotic Withdrawal Index. The Modified Finnegan's Neonatal Abstinence Scoring Tool is the most frequently used NAS assessment tool in the United States, validated in term infants with opioid exposure, but assessment of preterm infants and those babies exposed to multiple drugs in utero adds to the variability in clinical presentation.

There are many unanswered questions regarding the best practices surrounding evaluation, treatment, and dosing for NAS pharmacological interventions. Many research and operational questions remain on how to consistently provide high-quality care in an unbiased and compassionate manner. States are taking steps to address the gaps in knowledge regarding NAS through interdepartmental efforts, perinatal learning collaboratives, and quality improvement initiatives.

A state-level approach to NAS can address several levels of intervention, including:

- Surveillance for NAS-affected infants and the sources of maternal opiate use.
- Reimbursement for utilizing screening protocols to detect substance abuse early in pregnancy and withdrawal signs in newborns.
- Development of better measures to ensure follow-up with opioid-dependent women and receipt of comprehensive services.
- Collaborative efforts to strengthen clinical standards for identification, management, and follow-up with NAS-affected infants and their families.

II. Introduction

Over the last decade, there has been increasing public health, medical, and political attention paid to the parallel rise in two trends: an increase in the prevalence of prescription opioid abuse and an increase in the incidence of NAS. The two trends are likely intertwined, but many questions remain about the nature of the NAS “epidemic” and how best to screen for affected infants and manage their symptoms.⁶ In utero exposure to certain drugs can cause neonatal withdrawal after birth when the drug is abruptly stopped because the infant—like the mother—has developed physical dependence on the drug.⁷ Clinically relevant neonatal withdrawal most commonly results from in utero opioid exposure but has also been described in infants exposed to benzodiazepines, barbiturates, and alcohol. NAS refers to the constellation of clinical findings associated with opioid withdrawal that usually manifests as neurological excitability, gastrointestinal dysfunction, and autonomic overreactivity.⁸ Infants diagnosed with NAS are a subset of the larger group of all opioid-exposed infants, about 55 percent to more than 90 percent of whom develop withdrawal signs and require pharmacotherapy. There may be maternal or infant factors affecting the expression of NAS, but these factors are not understood well enough to serve as conclusive predictors of NAS symptoms’ severity.⁸ State health agencies play a key role in collecting accurate data to track trends and supporting evidence-informed practices to screen, manage, and prevent opioid dependency in mothers and infants.

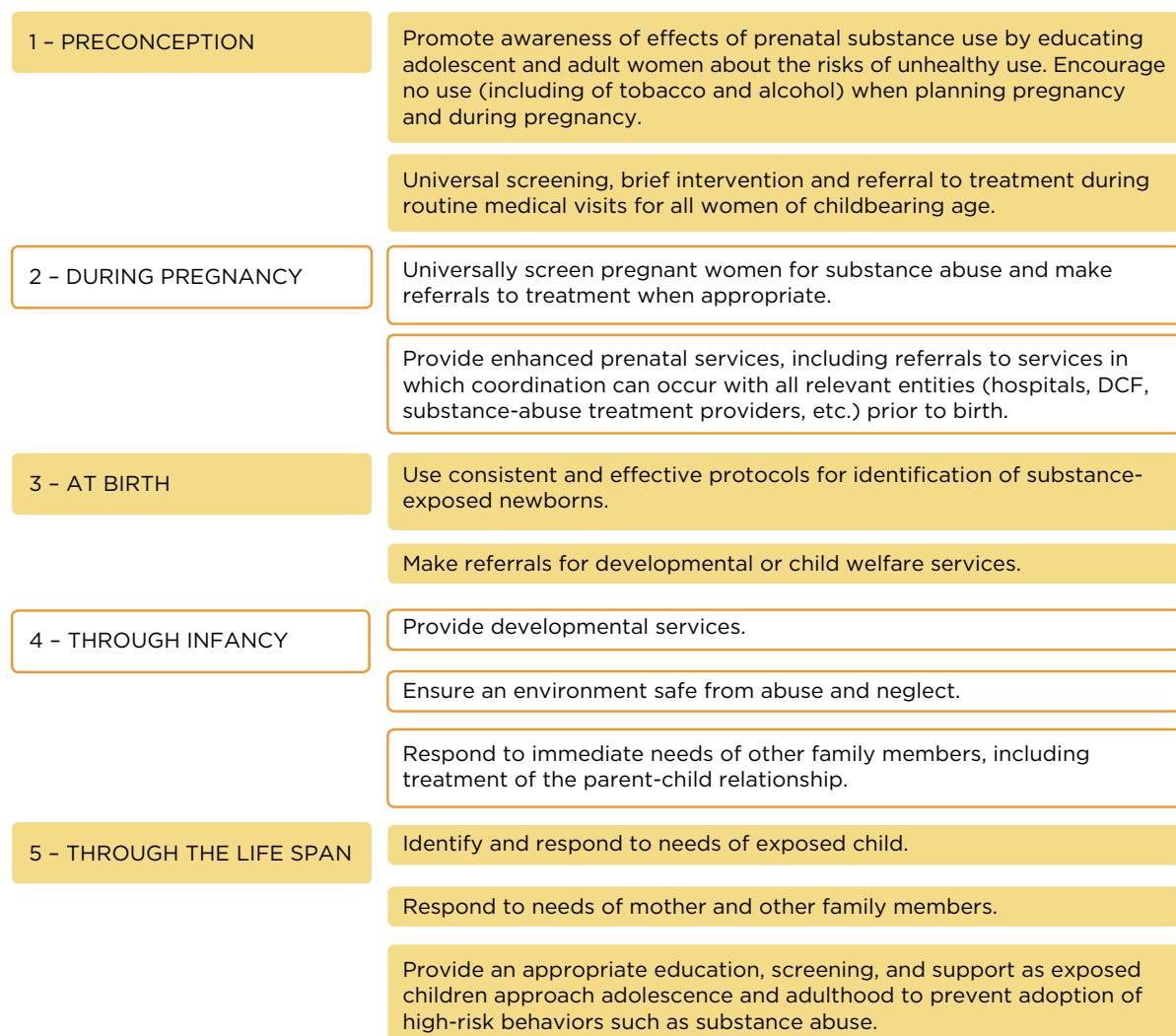


Prevention and intervention opportunities to avert or ameliorate the outcome of NAS can be considered along a continuum of care spanning time frames in the mother’s life and that of her child. The 2009 Substance Abuse and Mental Health Services Administration’s (SAMHSA) report, “Substance-Exposed Infants: State Responses to the Problem,” provides a five-point intervention framework to organize the prevention and intervention opportunities that can impact outcomes for opioid-dependent women and their children.⁴ The five time frames for intervention include:

1. Preconception period.
2. During pregnancy.
3. At birth.
4. Postpartum or neonatal/infancy period.
5. Childhood and beyond.

Primary prevention of NAS encompasses efforts to raise awareness about the risks associated with the use of prescribed opioid narcotics with the goal of preventing addiction in all women of reproductive age, as well as assessing and treating any unhealthy use prior to conception. During pregnancy, universal screening efforts and enhanced substance abuse services—including accessible medication-assisted therapy (MAT) for all women who need it—are important goals. At birth, the systematic approach to screening infants, monitoring for withdrawal signs using a scoring tool, and managing care for the mother and infant offer numerous opportunities for improving outcomes. Enhanced services for the family (i.e., family-centered services) should also be considered for the infant's optimal care and development over the long term. **Figure 1** provides some key strategies to consider during each of the five time periods. Because the points of potential intervention span multiple phases in women and children's lives, many state agencies, healthcare providers, and community-based services are involved. There are several points when a woman or her family can be lost to follow-up, such as during the handoff between agencies or providers. State health agencies play a key role in linking various resources and providers by tracking substance-exposed infants through screening, assessment, and service delivery.⁴

FIGURE 1: INTERVENTION POINTS TO PREVENT PRENATAL SUBSTANCE EXPOSURE AND AMELIORATE THE IMPACTS OF SUBSTANCE-EXPOSURE IN INFANCY



III. Background

There has been a significant increase in the national prevalence of NAS. As reported in the 2012 article “Neonatal abstinence syndrome and associated health care expenditures,” the diagnosis of NAS increased from 1.20 per 1,000 hospital births in 2000 to 3.39 per 1,000 hospital births in 2009.³ This means that in 2009, there were more than 13,000 infants diagnosed with NAS, or approximately one infant born every hour in the United States had signs of drug withdrawal.³ The rise in NAS births goes hand-in-hand with a significant increase in prevalence of mothers dependent on or using opiates at the time of delivery from 2000-2009, with 5.63 cases of maternal opiate use per 1,000 hospital births in 2009.³ However, the population of pregnant women with opioid dependence is varied, and their circumstances span the spectrum from heroin addiction, polydrug abuse, prescription opioid abuse, MAT (methadone maintenance or buprenorphine maintenance), and chronic opioid use prescribed for medical indications. State health agencies and clinical providers need to keep in mind these differing contexts to effectively screen for opioid dependency among women and identify risk factors in women and infants with potential opioid exposure.

The potential link between the trend in NAS prevalence and the increasing trend of prescription opioid abuse and chronic opiate use is a public health concern. From 1999-2009, there have been steady increases in prescription opiate sales, substance abuse treatment admissions, and overdose deaths due to prescription opiates. Nonmedical use of prescription drugs is the third most common drug category of abuse after marijuana and tobacco.⁹

There has been a 33 percent increase in nonmedical use of prescription opioid pain relievers among pregnant women in the last decade.² One percent of pregnant women in 2005-2006 and 0.7 percent of pregnant women in 2007-2008 reported nonmedical use of opioid pain relievers (a rate of 7-10 per 1,000 pregnancies). This translates to 17,000 (2007-2008) to 25,000 (2005-2006) affected pregnancies as an annual average, ranking only behind marijuana use in absolute numbers.¹⁰

Nonmedical use or misuse of opioid pain relievers is a broad category, defined as the use of a narcotic pain reliever without a prescription, in a way other than as prescribed, or for the experience or feeling the drug causes.¹¹ It can precede, but does not necessarily lead to, prescription opioid abuse and addiction. Also of concern are some indicators of increasing prescription narcotics use by pregnant women for medically-indicated reasons. In one study, chronic use of narcotic prescriptions for at least one month during pregnancy increased five-fold between 1998 and 2008, from about 2.5 cases per 1,000 deliveries to more than 10 cases per 1,000 deliveries.¹²

NAS is associated with an increased risk of complications in the neonatal period and higher costs to the healthcare system, particularly Medicaid. NAS increases the risk of respiratory complications at birth, low birthweight, prematurity, feeding difficulties, and seizures.^{3,13} Medicaid covers the majority of mothers with opiate exposure during pregnancy (60%) and infants diagnosed with NAS (78%). Hence, states are well positioned to deal with the increasing numbers of opioid-dependent pregnant women



and NAS-affected infants.³ States are seeing the impact of this diagnosis on Medicaid expenditures and budgets. In Vermont, more than 90 percent of deliveries to women with opioid dependency were Medicaid deliveries.¹⁴ Tennessee's Medicaid program, TennCare, covered 75-87 percent of infants diagnosed with NAS from 2008-2011. TennCare estimates suggest that care of infants born with NAS exceeds \$40,000 in the first year of life, which is nine times the cost of care for otherwise healthy infants.¹⁵

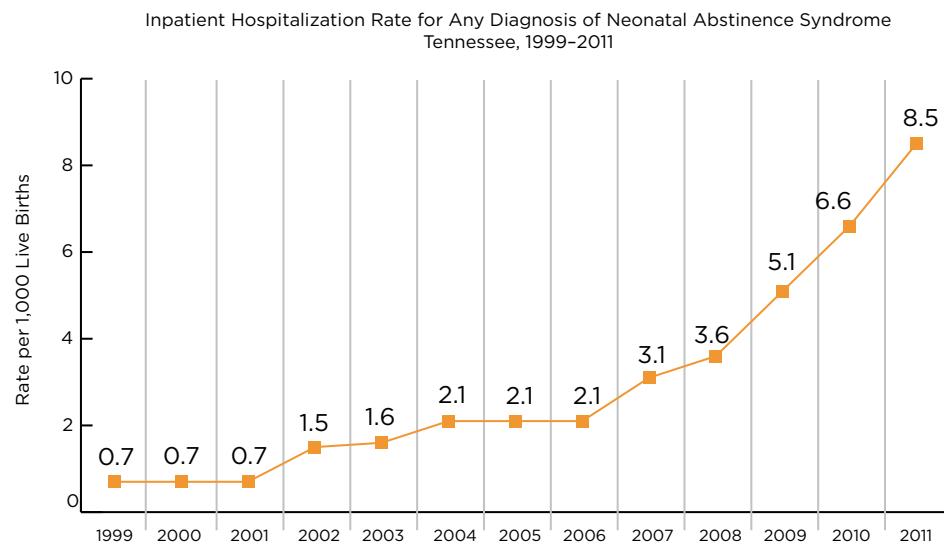
State health agencies can examine ways in which they may support better outcomes for mothers and infants affected by opioid dependency. For example, state health agencies may:

- Collect data on the number of cases of substance-exposed infants and NAS, respectively. Also, they may track the source of the maternal substance use, which will help better describe the causes of infant NAS cases and inform prevention and treatment efforts in the preconception and prenatal periods. This may be done through mandatory reporting.
- Support provider education and public awareness efforts to increase provider-patient discussion on the risks and benefits of chronic opioid therapy and the importance of concurrent contraception to reduce unintended fetal exposure to the drugs.
- Extend Medicaid coverage for substance abuse screening at preventive care visits, preconception visits, and prenatal visits.
- Educate providers on the use of validated substance abuse screening tools as the standard of care for all obstetric patients.
- Review policies on substance use/abuse in pregnancy in a public health framework, rather than with a criminal or punitive framework, to increase opportunities to engage mothers in screening, counseling, and treatment for their addiction.
- Streamline entry points for substance abuse treatment.
- Support innovation to bring more family-centered, comprehensive and wrap-around services to encompass mental healthcare and substance abuse treatment as a way of increasing access to these services in the prenatal and postpartum/interconception period.
- Identify and help address the different service delivery issues for the provision of methadone maintenance and buprenorphine maintenance.
- Build a model of a continuum of substance abuse services and treatment capacity that better links women with the appropriate level of community-based services whenever possible.
- Encourage information sharing among birthing hospitals and perinatal providers to advance the knowledge base on how to optimize screening, diagnosis, and management (both pharmacotherapy and non-pharmacological care) of opioid-exposed newborns and those diagnosed with NAS.
- Strengthen collaborations between clinical providers, community agencies, home visiting programs, and state agencies to track drug-exposed women and their infants through the first year of life. Infants with NAS may have subacute symptoms—such as poor feeding, difficulty sleeping, and loose stools—for months after birth. These prolonged NAS symptoms, along with other variables such as family characteristics and functioning and environmental deprivation, may put the infant with NAS at risk for failure to thrive, child abuse or neglect, and developmental delay.

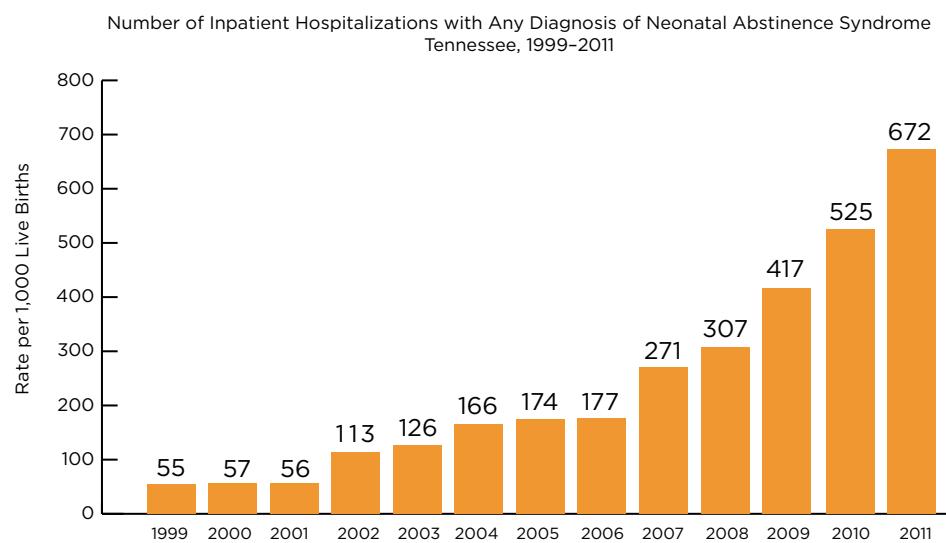
IV. State Surveillance and Key Data to Inform NAS Trends

States are seeing a significant rise in affected infants. In Tennessee, there has been a 10-fold increase in NAS cases since 1999 [Figure 2]. The rate of NAS cases was 0.7 per 1,000 live births in 1999 and 8.5 per 1,000 live births in 2011. The Kentucky Division of Public Health reports an 11-fold increase in NAS cases, from 1.2 cases per 1,000 live births in 2001 to 13.2 cases per 1,000 live births in 2011.^{16,17} In Florida, the rate of infants diagnosed with NAS increased more than three-fold in a six-year period, from 2.31 infants diagnosed per 1,000 live births in 2007 to 7.52 per 1,000 live births in 2011.¹⁸ In Vermont, 26 per 1,000 deliveries involved an infant diagnosed with NAS in 2010 (n=162), up from three per 1,000 deliveries in 2002.¹⁴ Washington state has also reported a significant increase in NAS rates, from 1.2 per 1,000 live births in 2000 to 3.3 per 1,000 live births in 2008. Data from Washington reveals that prenatal exposure to opioids increased from 11.5 percent of all drug-exposed neonates in 2000 to 24.4 percent in 2008, and 41.7 percent of infants diagnosed with NAS were exclusively exposed to opioids.¹³

FIGURE 2



Data Sources: Tennessee Department of Health; Policy, Planning and Assessment; Birth Statistical and Hospital Discharge Data Systems



Data Sources: Tennessee Department of Health; Policy, Planning and Assessment; Birth Statistical and Hospital Discharge Data Systems



TENNESSEE: State Data Is Providing Key Insights into the Causes of NAS Trends

Tennessee health officials recognized the importance of accurate and real-time data on NAS trends to help measure the impact of interventions to prevent NAS and better manage NAS-affected infants and mothers. The state commissioner of health made NAS a reportable condition as of Jan. 1, 2013, and a web-based reporting portal is available on the Tennessee Department of Health website. One piece of information captured in the portal is the source of maternal opiate use, a key factor that can be obtained through provider case reports. This data from Tennessee reveals the causes of the state's NAS increase. As of Dec. 7, 2013, 805 NAS cases have been reported to the Tennessee Department of Health. Of these cases, nearly 46 percent resulted from the mother being on supervised MAT, 39 percent were due to prescription opioid abuse, and 19 percent were due to supervised pain therapy. Illicit opiate use accounted for 28 percent of the NAS cases reported.¹

Tennessee has also examined its Medicaid claims data to gain insights into opportunities for intervention to prevent and treat opioid dependence in pregnancy. The number of women in TennCare prescribed narcotics for more than 30 days and concurrently prescribed contraceptives was particularly revealing: 82 percent of these women were on narcotics, but not on contraceptives. This is a missed opportunity for primary prevention and suggests an area for targeted education to raise awareness among providers and women. TennCare used the ICD-9 code 779.5, corresponding to drug withdrawal syndrome in the newborn period, to determine the incidence rate of NAS among its enrollees. The mother's length of Medicaid eligibility in the year prior to birth was also examined to get a picture of when mothers were entering the TennCare system and the potential duration for prenatal management. On average, TennCare spent almost \$41,000 per NAS case in 2010, compared to about \$4,000 for an otherwise healthy birth. Other data also indicate that infants born with NAS are 14.8 times more likely to be in child protective custody at some point in their first year of life compared to other TennCare infants. Thus, the overall costs of NAS are far greater than medical care and extend beyond the newborn period.

¹Multiple maternal substances may be reported, therefore the number of cases may not add up to 100 percent.

Source: Tennessee Department of Health. "Neonatal Abstinence Syndrome Surveillance Summary, For the Week of December 1-December 7, 2013. Week 49." Available at http://health.tn.gov/MCH/PDFs/NAS/NASsummary_Week_49.pdf. Accessed 12-10-2013; TennCare Office of Healthcare Informatics. "Neonatal abstinence syndrome among TennCare enrollees." Presentation. 9-18-2012.

Like Tennessee, other states are finding ways to make NAS a reportable condition. Kentucky recently passed a bill mandating reporting of all NAS cases to its state health department. The causes of NAS likely vary between states, so it is important for each state to track its own data on the maternal source of opiates. The data can then be used to inform preventive efforts that will decrease opioid dependency among pregnant women and the occurrence of clinically significant NAS.

V. Primary Prevention: The Preconception Period

PRESCRIBING CONTROLLED SUBSTANCES

The preconception period is the ideal point to intervene and prevent an opioid-exposed pregnancy. In 2009, the American Pain Society and the American Academy of Pain Medicine wrote, “Clinicians should counsel women of childbearing potential about the risks and benefits of chronic opioid therapy during pregnancy and after delivery” and try to minimize use of opioids during pregnancy based on a risk-benefit assessment.¹⁹ With more women of childbearing age using prescription narcotics, state health agencies can support education and awareness efforts to increase provider-patient discussions about the risks of misuse, addiction, and the potential risks to infants exposed in utero to these drugs, as well as conversations about the importance of concurrent contraception to reduce unintended fetal exposure to the drugs. Prescribing clinicians should also obtain a patient’s records from the state prescription drug monitoring program to help assess the patient’s history of exposure and any other sources of prescription opioids.¹⁹

To advance its NAS work, Tennessee formed a NAS Subcabinet Working Group, which aims to reduce the number of women on prescribed narcotics having unintended pregnancies. The subcabinet, along with many other states, signed a letter to FDA petitioning for a “black box” warning on certain narcotics to increase NAS awareness and communication between providers and patients. TennCare plans to require that narcotic prescribers counsel women of childbearing age about the risks of becoming pregnant while taking narcotics and discuss birth control options before prescribing the drugs. Such counseling will be part of the prior authorization process for certain narcotics. In Florida, the Statewide Task Force on Prescription Drug Abuse and Newborns recommended provider training on drug screening protocols and pain management education in medical schools, as well as a public awareness initiative to educate the public on the dangers of prescription drug abuse during pregnancy.¹⁸

SUBSTANCE ABUSE SCREENING

Taking a public health approach to routine screening for unhealthy substance use in women at every healthcare visit can help increase the opportunities for primary prevention. There are validated screening tools, such as the “4 P’s” or the Screening Brief Intervention and Referral to Treatment (SBIRT) model, which can be administered when a woman interacts with the health system, particularly at annual preventive care visits and preconception visits. Applying universal screening practices reduces the “stigma that occurs when only a portion of the population is screened and normalizes dialogue and education about substance use in the healthcare setting.”²⁰ However, barriers to regular screening for substance use exist and need to be addressed, including providers’ inability to obtain reimbursement for screening, lack of provider time, lack of familiarity with screening procedures and referral options, lack of information or misinformation about substance use among pregnant women, doubts about the benefits of treatment, discomfort with the subject, and cultural and language barriers.²⁰ Some of these barriers can be addressed at the state level through Medicaid coverage of substance abuse screening, provider education and training, and streamlining entry points for substance abuse treatment.

VI. Prenatal Care: Identifying and Managing Opioid Dependency

PRENATAL SCREENING

The ACOG Committee on Health Care for Underserved Women has stated that all women should be routinely asked about alcohol and drug use, including the use of prescription opioids and other medications for nonmedical reasons.²¹ ACOG endorses using a validated tool, such as the 4 P's, to screen all patients early in their pregnancy. Urine drug tests should supplement the medical history and physical exam and be performed with the patient's consent and in compliance with state laws. Women should be informed of the potential consequences of a positive test result, including any mandatory reporting requirements.²¹

States can support the ACOG recommendation for universal substance use screening in early pregnancy in a variety of ways. State agencies, quality improvement efforts, and perinatal collaboratives can help advance prenatal screenings as the expected standard of care for obstetric providers. Some states, such as West Virginia, have mandated prenatal risk screening. In May 2008, West Virginia passed the Uniform Maternal Screening Act requiring that all healthcare providers offering maternity services use the West Virginia Prenatal Risk Screening Instrument. The screening tool collects information on conditions, demographics, and behaviors, such as substance use, that may put a woman at greater risk for a poor pregnancy outcome. States can also ensure that their Medicaid program reimburses

for prenatal substance use screening. There is no federal mandate for covering screening, but more than 20 states have added SBIRT coverage to their Medicaid programs, and private insurers should be encouraged to do the same.²⁰

It is also important to consider the implications of identifying prenatal substance abuse in efforts to increase access to care and improve clinical outcomes. Framing the problem as a public health issue rather than a criminal issue may be helpful as one examines state policies to ultimately prevent and reduce NAS cases. For example, 16 states consider substance abuse during pregnancy to be child abuse under civil child welfare statutes.²² However, a punitive



atmosphere has been linked to women with substance abuse problems avoiding prenatal care or treatment for fear of losing custody of their children.²³ The American Medical Association has rejected the idea of criminalizing pregnant women for using drugs.²⁴ Some states have proposed or taken steps to provide immunity to pregnant women seeking prenatal care.¹⁸ For example, HB 12-1100 was signed into Colorado law on March 9, 2012, and prohibits information obtained during a drug screen or test performed as part of prenatal care from being admissible in criminal proceedings. There are already many other barriers to accessing substance abuse treatment services, and punitive laws that do not differentiate those women who comply with referrals and treatment can be a deterrent to accessing those very services that have shown to improve maternal and neonatal outcomes.

MEDICATION-ASSISTED TREATMENT DURING PREGNANCY

Methadone maintenance treatment is the standard of care for opioid-dependent pregnant women. State health agencies can help optimize service delivery and treatment capacity to ensure women have access to needed services in a timely manner, staying in their community or medical home whenever possible. Compared to medication-assisted withdrawal, methadone maintenance is associated with better relapse prevention, decreased exposure to illicit drugs and other high-risk behaviors, improved adherence to prenatal care, and improved neonatal outcomes.^{21,25-27} The goal of maintenance therapy is to prevent withdrawal during pregnancy and minimize fetal exposure to illicit substances.²

Methadone exposure in utero may also result in NAS incidences, but maternal methadone doses have not been consistently found to correlate with the severity of NAS.²⁸⁻³⁴ Data from a meta-analysis did not show a statistically significant difference in the incidence of NAS among women on lower versus higher methadone doses.³⁵ Methadone should be dosed to avoid withdrawal symptoms in the pregnant patient and block the euphoric effect of misused opioids.²¹ However, the woman's system will metabolize and distribute methadone differently during pregnancy, so dosages will likely need to be adjusted; having women on too low a dose has been associated with an increased risk of relapse.³⁶



Although MAT is a centerpiece of managing opioid dependency in pregnancy, it is best applied as part of a comprehensive treatment program that includes obstetric care, counseling, and wrap-around services.² There is a treatment gap in pregnant women's receipt of substance abuse services overall: In 2005, only 6 percent of the pregnant women classified as needing alcohol or illicit drug use treatment actually received it.⁴ Substance abuse treatment admissions of pregnant women comprised 3.9 percent of all female admissions in 2005.⁴ Pregnancy is an important period for offering services because of the potential far-reaching impact they can have on infant outcomes, but pregnancy also presents challenges to accessing services. Barriers to care may include lack of transportation, lack of child care services, intensive time requirements, additional costs and copays, and stigma.³⁷ The federal Substance Abuse Prevention and Treatment Block Grants require that states set aside a certain proportion of their block grant funds for services designed for pregnant women and women with dependent children. Such women should receive priority access to treatment and provision of services within 48 hours of request.⁴ Among all types of substance abuse treatment facilities, 7 percent offer prenatal care services, 8 percent offer child care services, and 14 percent offer special programs for pregnant or postpartum women.²³ Methadone treatment centers serve the greatest proportion of female substance abuse clients and often have special programs for pregnant women, but only a limited number provide child care services. Such programs should research innovative ways to provide child care services and evaluate the impact, if any, on treatment outcomes and retention.²³

Buprenorphine is another option for medication-assisted therapy of opioid dependency. Increasing evidence on maternal and neonatal effects is informing buprenorphine's role in the continuum of care and its safety profile as part of a treatment program. Buprenorphine has some key differences from

methadone in its pharmacological action: It is a partial—not complete—opioid agonist, so it acts as an opioid receptor agonist at low doses and as either an agonist or antagonist at high doses.² There is lower risk of overdose with buprenorphine because there is a ceiling effect on respiratory suppression. The single-agent formulation without naloxone (Subutex) is preferable in pregnancy but does have the higher potential risk of abuse or diversion.²¹ The properties of buprenorphine are not as well-suited for patients who have high opiate needs as methadone, and there is some evidence that there is higher attrition of patients when initiating treatment with buprenorphine compared to methadone.^{38,39}

Because buprenorphine can be prescribed by physicians in office settings, providing buprenorphine offers a different model of delivery compared to the highly regulated methadone treatment programs. Physicians can obtain a special SAMHSA waiver to prescribe buprenorphine in a medical office setting. Office-based treatment potentially reduces the stigma of opioid maintenance therapy and increases its availability, especially in rural areas.^{21,40} In 2008, more than 2 million buprenorphine prescriptions were issued to 300,000 patients nationally, and almost 14,000 providers have been authorized to prescribe the drug.² However, the patient's clinical and psychosocial needs must be considered when selecting the appropriate drug for opioid maintenance therapy. Some women may benefit from the more structured, regulated methadone treatment programs. Access to wrap-around support services, such as mental health counseling, nutrition, and social service referrals, may also vary more in the office-based delivery model because access would then depend on individual providers' referral practices.⁴¹



VERMONT: Designing a Regionalized, Integrated System for Opioid Dependence Treatment

Each year, more Vermont residents seek treatment for opiate addiction. Methadone treatment programs' limited availability and capacity has led to broader use of buprenorphine services than originally anticipated. Although this has increased access to MAT, there have been challenges: Patients require more physician time, counseling services are not always readily available, and reports of drug diversion have increased.

Vermont's approach to healthcare reform supports making opioid screening and MAT an expected component of care provision within health homes. Vermont's 2012 Medicaid Health Home Program proposal suggests having buprenorphine prescribers, working in conjunction with nurses and substance abuse and mental health counselors, serving about two-thirds of opioid-dependent patients in their communities. Only more complicated patients would need to be cared for in methadone treatment programs. This "hub-and-spoke" model works to integrate addiction treatment services along a continuum of care, allowing more women to stay within their communities and access addiction and mental health services with primary care services.

Source: Vermont Agency of Human Services. "Integrated treatment continuum for substance use dependence 'Hub/Spoke' Initiative—Phase 1: Opiate dependence." January 2012.



Data on the neonatal effects of buprenorphine, although not as complete as the evidence base for methadone, suggest that buprenorphine exposure results in a less severe NAS manifestation. During pregnancy, placental transfer of buprenorphine may be less than for methadone, thereby reducing fetal exposure.^{42,43} Fetal monitoring also suggests that buprenorphine causes less fetal cardiac and movement suppression than methadone.⁴¹ Based on a double-blind, double-dummy, randomized, controlled study, buprenorphine has been shown to result in less severe NAS with infants requiring less total morphine for treating withdrawal symptoms, a shorter duration of treatment, and shorter hospital stay.^{39,43,44} The long-term data on infant and child outcomes following in utero exposure to buprenorphine are not yet available, however, so women should be cautioned when consenting to MAT.²¹

COORDINATION OF CARE FOR OPIOID-DEPENDENT WOMEN

Finally, innovation and quality improvement should play a role in standardizing opioid-dependent women's prenatal care to deliver comprehensive, coordinated services. Half to three-quarters of opioid-dependent women also have a mood or major psychiatric disorder, necessitating ongoing coordination of mental health services and possibly medication.^{25,45,46} Women's psychiatric comorbidities can affect their outcomes in substance abuse treatment: Those with anxiety disorders are more likely to be compliant with treatment, while women with mood disorders are more likely to be positive for drugs while in treatment.⁴⁵ Opioid-dependent women are also at risk for polydrug use, which can potentiate the expression and severity of NAS in their infants.^{47,48} In some studies, around 90 percent of opioid-dependent pregnant women have been reported to smoke heavily, and smoking is known to affect birthweight and could affect NAS as well.^{27,39,49} Pregnant women with complex issues would benefit from wrap-around services linked to a medical home and a specific provider to coordinate care.

State health agencies can support innovation and quality improvement initiatives to improve the model of care coordination for opioid-dependent women. Structural changes to the delivery of prenatal care may be needed to accommodate the increased role for care coordination of complex patients to include longer appointment times, more frequent visits, multidisciplinary case reviews, and cross-discipline strategies to increase medication adherence, such as linking a medication dose with a prenatal visit or counseling requirement.^{1,2} To inform service delivery models and innovation, states should support data collection systems to better track the number of pregnant women referred for treatment services and treatment outcomes for women identified through prenatal screening.⁴

VII. Care of the Neonate: Diagnosing Withdrawal Signs

State health agencies can support a standardized approach to NAS diagnosis by:

- Encouraging all birthing hospitals to have a written policy on the criteria for screening and testing women and infants for substance exposure.
- Encouraging the use of an NAS screening tool as the standard of care for monitoring infants.
- Working with child protection service (CPS) agencies to review and train staff on policies for reporting substance-exposed newborns.
- Tracking outcomes for CPS referrals made for NAS.

Nearly all opioid-exposed infants will display some NAS symptoms, but only a subset of infants will need pharmacotherapy.⁵ Opioid receptors are concentrated in the central nervous system and the gastrointestinal tract, so the predominant signs and symptoms of opioid withdrawal manifest as central nervous system irritability, autonomic overreactivity, and gastrointestinal dysfunction.⁸ NAS affects infants' self-organization and self-regulation, interfering with basic functions such as feeding, sleeping, and the ability to be alert and communicate clear cues to caregivers.⁵ The onset of symptoms depends on the type of drug(s) used, as well as other maternal and infant factors such as metabolism, birthweight, and gestational age at birth. Heroin exposure usually results in NAS symptoms within 24 hours of birth, whereas methadone withdrawal usually manifests within 72 hours of birth and may last several days to weeks.^{21,50} Withdrawal symptoms following buprenorphine exposure appear to emerge later, so infants may need to be observed longer in the hospital.⁴³



Infants at risk for NAS also have an increased risk of certain complications in the neonatal period. NAS is associated with an increased risk of respiratory complications at birth, low birthweight, prematurity, feeding difficulties, and seizures.^{3,13} In Tennessee, Medicaid claims data found that infants diagnosed with NAS were three times more likely to be low birthweight, with more than 33 percent of these infants weighing less than 2,500 grams at birth.⁵¹ One study found a higher risk of some congenital heart defects and other birth defects following maternal use of prescribed opioid narcotics early in pregnancy, but there are no other reports of such an association in the recent literature.⁵²

MATERNAL AND INFANT SCREENING

There are numerous approaches to screening for NAS in neonates and their subsequent management. The American Academy of Pediatrics recommends that every nursery caring for infants with NAS develop a protocol that defines the indications and procedures for screening for maternal substance abuse, as well as a standardized plan for the evaluation and comprehensive treatment of infants at risk or showing signs of withdrawal.⁸ However, a national survey of neonatology divisions revealed that

only 55 percent of respondents had a written policy addressing NAS management. Seventy percent of neonatal intensive care units (NICU) always use an abstinence scoring tool to determine when to start, titrate, or stop pharmacological therapy, and 83 percent routinely perform toxicological screening on infants' urine or meconium before starting treatment.⁵³ Maryland and Iowa have also published results from surveys of birthing hospitals revealing similarly high variability in practice around detecting and managing NAS. In Maryland, half of the hospitals responding had a standardized evaluation and treatment protocol for NAS, but only 30 percent of hospitals observed drug-exposed infants longer than 48 hours postpartum.⁵⁴ In Iowa, 25 percent of birthing hospitals had a structured protocol that guided neonatal drug screening, 60 percent of hospitals screened on an arbitrary basis, and 15 percent did not perform any screening.⁵⁵ Having a screening protocol that guides decisionmaking can help reduce testing bias, which has been reported to result in more drug testing of poor and racial or ethnic minority women.⁴

Screening for NAS should begin with a careful maternal history and physical examination and supplemented with toxicological testing as needed. Maternal report of substance use, late entry into care or no prenatal care, previous unexplained late fetal demise, precipitous labor, and placental abruption are among the risk factors that could prompt the observation and, in some cases, testing of infants for drug exposure.⁸ Urine toxicological screening can be done on either the mother or infant. For the infant, the urine specimen should be collected as soon as possible after birth and will only reflect recent drug exposure because opioid metabolites are cleared within one to three days after birth.⁸ Meconium analysis reflects drug exposure during the previous several months in utero, but results are usually not available for several days and thus, cannot guide real-time management of the newborn.² Newer laboratory testing is available on specimens such as umbilical cord blood, and research is being done to examine their utility in the screening for NAS.

Infants who are exposed to opioids should be observed in the hospital for four to seven days and their symptoms assessed with the aid of an abstinence scoring tool. Regularly and accurately using a screening tool can improve decisionmaking about whether to initiate pharmacological therapy and provide quantitative feedback to guide dosing and weaning.

There are a few different scoring tools used in hospitals today. The most frequently used tool is the Modified Finnegan's Neonatal Abstinence Scoring Tool, which assigns a cumulative score based on interval observations of 21 items relating to NAS symptomatology.^{8,53} The modified Finnegan score is comprehensive, but it may also be too complex for routine use in many nurseries. The Lipsitz Neonatal Drug-Withdrawal Scoring System is an 11-item scale that is simpler to use.⁸ All scoring tools have limitations. Their accuracy is highly dependent on observer skill and training. Regardless of the method chosen, use of an abstinence scoring system results in more objective criteria for determining when pharmacological treatment is necessary. The AAP policy statement recommends adopting a protocol for the evaluation and management of neonatal withdrawal and providing training for staff in correct use and scoring procedures.⁸ The tools are validated for term infants, not preterm infants, who appear to have a different course of NAS.⁸ The screening tools were designed for opioid withdrawal, but infants with polydrug exposure in utero will have varied symptomatology. For example, benzodiazepine



exposure prolongs the course of withdrawal, and selective serotonin reuptake inhibitors increase the risk of seizures.^{6,27,31} Finally, there is no known optimal threshold score for starting pharmacological therapy for any of the published screening tools.⁸

LEGAL CONSIDERATIONS

Diagnosing opioid-exposure and withdrawal accurately in infants has implications for the family beyond the medical arena because of child protection laws that require reporting. The Child Abuse and Prevention Treatment Act requires that states have policies and procedures in place to notify CPS agencies when an infant is affected by illicit substance abuse or withdrawal symptoms resulting from prenatal drug exposure.⁵⁶ CPS agencies are then responsible for assessing the level of risk for the exposed newborn and other children in the family.⁵⁷ A 2002 survey of 166 hospitals nationwide revealed that, of the one-third with substance exposure protocols for newborn care, only about half of the protocols included instructions for reporting to external agencies. Different states have different criteria for reporting. In Florida, a mother's report of having used illicit substances or alcohol during pregnancy is sufficient to file a report with CPS. In Iowa, the presence of an illicit substance in the infant's system must be documented by laboratory testing, independent of parental disclosure. In Colorado, it is necessary to medically document a negative fetal or neonatal outcome related to perinatal illicit drug exposure to file a CPS report.⁵⁵ As noted previously, Colorado also enacted legislation (HB 12-1100) that protects from use in criminal proceedings any information or test results related to substance use that was obtained as part of a woman's prenatal care. In addition, a lack of communication between obstetric providers, pediatricians, and nursing staff add to the complexities around reporting.⁴

VIII. Management of NAS

NON-PHARMACOLOGICAL CARE

Non-pharmacological management should be the standard of care for all opioid-exposed infants to help them sleep, eat, gain weight, and interact with caregivers.⁵⁸ Non-pharmacological interventions include minimizing stimuli such as light and sound, avoiding infant autostimulation by careful swaddling, responding early to an infant's signals, adopting infant positioning and comforting techniques such as swaying, rocking, and pacifier use, and providing frequent small volumes of feeds to allow for adequate growth.^{5,8} If there is no contraindication, such as HIV infection, mothers should be encouraged to breastfeed because it has been associated with ameliorating and delaying withdrawal symptoms, even after adjusting for prematurity and polydrug exposure.^{8,44,59} For mothers on methadone maintenance, the drug's concentrations in breast milk are low and unrelated to the maternal dose.⁶⁰

Infants who are being observed for withdrawal need to be continuously monitored, such as with pulse oximetry or a cardiorespiratory monitor, but if this can be conducted using a mother-baby unit, then there is more opportunity to support mother-infant bonding. Some evidence indicates that the site of care may influence short-term outcomes. For example, infants who room-in with mothers instead of being transferred to a NICU had an increased likelihood of being discharged home with their mother and a decreased need for NAS drug therapy.^{61,62} Parental support and teaching can be crucial for mothers who may be dealing with feelings of guilt and anxiety upon witnessing their infants' symptoms of withdrawal. Substance abuse, mood disorders, and adverse childhood experiences may also affect

mothers' abilities to respond to infant cues. Partners or relatives seeing the newborn with NAS may blame the mother for her drug dependency, which can add to maternal distress or precipitate abusive or violent confrontations.⁵ Positive role modeling by healthcare providers on how to recognize and respond to infants' cues can help set the tone for mother-infant attachment and healthy interactions.

PHARMACOLOGICAL MANAGEMENT

Pharmacological management is indicated to relieve moderate to severe signs of NAS and prevent complications such as fever, weight loss, and seizures if an infant is not responding to non-pharmacological support. Pharmacological therapy, however, should be undertaken with caution because it can lengthen the hospital stay and may interfere with mother-infant bonding.⁸ The first-line therapy for opioid withdrawal is treatment with an opiate.^{50,63} Morphine is an option and used only in the inpatient setting. Methadone is another option and may be weaned after hospital discharge, but outpatient dosing

requires good follow-up and teaching for families.² Methadone has a variable half-life in infants, so the drug can accumulate in the infant and cause lethargy.⁵⁸ In Vermont's Fletcher Allen Health Care hospital, methadone is the standard of care for pharmacological NAS management, and infants have an average stay of 6.3 days compared to the national average of 16 days for treatment with morphine. The safety, feasibility, and efficacy of outpatient methadone treatment continues to be studied to identify pharmacological agents that would safely decrease the length of inpatient hospitalization in community hospitals and other settings. Buprenorphine is another potential new option for infant treatment, but this drug needs further study as a primary choice for NAS.⁵⁸ Clonidine and phenobarbital are drugs that may be used as adjunct therapy to the primary opiate treatment for NAS.⁶³ Adjunct therapy or specially tailored regimens may be particularly important for infants with withdrawal following polydrug exposure.⁵⁸



IX. Gaps in Knowledge: Improving Standards of Care for NAS

There are many unanswered questions regarding best practices on evaluation, treatment, and dosing of pharmacological interventions for NAS. Different or modified screening tools need to be tested for their ability to recognize withdrawal in preterm infants or infants exposed to multiple drugs.⁶⁴ Many researchers point to the need for randomized, controlled trials to examine different protocols for pharmacotherapy.⁶⁴ Length of stay in hospital is an often-cited measure for NAS treatment, but it may not have enough specificity to compare efficacy or quality of care. Other measures may also need to be adopted to gain a richer picture of NAS care, such as the number of opioid-dependent mothers who have an antenatal consult with a pediatrician, the time between initiation of pharmacological therapy and weaning, the number of infants rooming-in with their mothers, the breastfeeding rate upon hospital discharge, the number of infants discharged home with their parents, and the number who follow up for outpatient services.

Many states are taking the initiative to address knowledge gaps regarding NAS. For example, the Tennessee Initiative for Perinatal Quality Care is undertaking an NAS quality improvement project. Fifteen hospitals attended the February 2013 kickoff meeting. More than 40 hospitals have expressed interest in the Neonatal Quality Improvement Collaborative of Massachusetts' NAS project. In Ohio, six children's hospitals are collaborating on research to better diagnose and manage NAS. In Delaware, the Delaware Healthy Mother and Infant Consortium's Standards of Care Subcommittee will be examining the medical management of infants with NAS, while the Delaware Home Visiting Advisory Council is looking at the social support aspect of NAS to improve monitoring and follow-up for affected families. In addition, the Vermont Oxford Network, a voluntary network of more than 950 NICUs worldwide, launched an Internet-based quality improvement collaborative on NAS in January 2013. In support of its mission, the network maintains a database including information about the care and outcomes of high-risk newborn infants. The Vermont Oxford Network's objectives include: (1) developing and implementing a standardized process for the identification, evaluation, treatment, and discharge management of infants with NAS; (2) developing and implementing a standardized process for measuring and reporting rates of NAS and prenatal drug exposure; and (3) creating a culture of compassion, understanding, and healing for the NAS-affected mother and infant.³⁶ Applying quality improvement principles and sharing data in state and professional collaboratives will add to the knowledge base and help move systems toward better standards of care and better measures to evaluate NAS-related outcomes.



Ohio's Nationwide Children's Hospital: Quality Improvement Efforts Geared to Address Staff Concerns

Nationwide Children's Hospital (NCH) in Columbus, Ohio, saw a six-fold increase in the number of infants with NAS from 2004-2008. With an average length of stay of 31 days for infants diagnosed with NAS in 2009, NCH established a quality improvement team to reduce the length of stay to 24 days by the end of 2010. Based on a staff survey, the greatest challenges in caring for infants with NAS included poor or inconsistent communication between providers, subjectivity and lack of competency with the modified Finnegan scoring tool, stressful family dynamics, and discharge planning.

To shorten the stay, NCH developed a pharmacological protocol for initiating and weaning morphine, with phenobarbital or clonidine used as adjunct therapy for specific symptomatology. To enhance consistency and overall proficiency related to screening, training courses were implemented for nursing staff, with intensive training of "super users" to serve as in-house resources. As a result of staff training, inter-rater reliability of scoring using the Finnegan tool improved, and there was better assessment and documentation of withdrawal symptoms in the charts.

NCH formed an NAS taskforce, which holds monthly interdisciplinary collaborative meetings and is working to enhance antenatal communication between providers and continues to evaluate and respond to staff needs for education. Staff resources under development include a bedside resource packet, electronic medical record best practice alerts, and unit-based NAS committees.

Source: McClead R, Prasad M, Magers J, Bagwell GA. "Neonatal Abstinence Syndrome (NAS): Treating pregnant women and their newborns." National Prescription Drug Abuse Summit. Orlando, Florida. April 2-4, 2013. Presented at National Prescription Drug Abuse Summit, Orlando, Florida, April 2-4, 2013. Available at: <http://www.slideshare.net/OPUNITE/nas-treating-pregnantwomenfinal>. Accessed 7-31-2013.

X. Follow-Up and Provision of Ongoing Services for the Mother-Infant Dyad

The postpartum period is a time for planning and careful follow-up with mothers and infants affected by opioid dependency and NAS. Persistent, subacute symptoms of NAS, such as poor feeding, difficulty sleeping, and loose stools, can occur for months.⁵⁸ These symptoms may make the infant more difficult to care for and console. Mothers and caregivers may need additional supports to parent and gain positive reinforcement. Early bonding experiences can enhance attachment and reduce the risk of failure to thrive, child abuse, or neglect.⁴¹

Comprehensive discharge planning and postpartum care must also address the mother's substance abuse management and ongoing needs assessments for the infant and the family as a whole. For mothers on methadone maintenance, there is a risk of oversedation and overdose because the physiological drug requirement decreases after pregnancy.^{9,21} The few months after delivery are also a vulnerable time for relapse.² The interconception period is an important opportunity to try to maintain or engage mothers in substance abuse treatment, because mothers with an infant exposed to drugs are at higher risk for a subsequent drug-exposed pregnancy.^{4,57} A comprehensive approach that provides family-focused services over a continuum of care could link families to needed services such as substance abuse treatment, mental health services, early intervention, parenting support, and social services.⁴ Some models for service provision and case management include the community-based peer recovery worker, home-based services, and family treatment drug courts.²⁰

Because the data are difficult to interpret or otherwise sparse, there are still many unanswered questions about long-term outcomes for infants with NAS. Long-term outcomes result from the interplay of many variables, such as environmental deprivation, inadequate nutrition, family characteristics and functioning, and prenatal and postnatal stress. The multiplicity and co-occurrence of factors makes it difficult to separate out the effect of opioid exposure alone. Few studies have looked at children beyond the first few years of life.⁸ In early childhood, there is some evidence for detectable cognitive and psychomotor deficits among infants who were opiate-exposed.⁶⁵ Other longitudinal studies from the 1970s-1980s, however, suggest that infants under two years of age function within the normal range of development.⁶⁶ The severity of NAS symptoms, including the occurrence of seizures, has not been shown to be associated with differences in long-term outcomes.⁸ It is important to follow infants diagnosed with NAS and their families because they are a group that may experience negative sequelae, including toxic stressors, and may need access to a variety of services to support caregivers in their parenting role. State agencies should strengthen collaborations to track drug-exposed women, their infants, and families so they are not lost at points of transfer between providers or services.



XI. Conclusion

A state-level approach to NAS can address several levels of intervention, including:

- Surveillance for NAS-affected infants and the sources of maternal opiate use.
- Reimbursement for utilizing screening protocols to detect substance abuse early in pregnancy and withdrawal signs in newborns.
- Developing better measures to ensure follow-up of opioid-dependent women and receipt of comprehensive services.
- Collaborative efforts to strengthen clinical standards for identification, management, and follow-up of NAS-affected infants and their families.

Although much is known about how to manage opioid dependency in pregnancy and NAS, many research and operational questions remain regarding how to consistently provide good quality of care in an unbiased and compassionate manner. State health agencies, along with other agencies, professional networks, and community partners, have a unique contribution to make to the knowledge base and support of best practices in caring for women and their children affected by NAS.

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Appendix: State Index of Resources

FLORIDA

Statewide Task Force on Prescription Drug Abuse & Newborns. "February 2013 Final Report." Available at: [http://myfloridalegal.com/webfiles.nsf/WF/RMAS-94LJPF/\\$file/Statewide_Task_Force_on_Prescription_Drug_Abuse_and_Newborns_Final_Report.pdf](http://myfloridalegal.com/webfiles.nsf/WF/RMAS-94LJPF/$file/Statewide_Task_Force_on_Prescription_Drug_Abuse_and_Newborns_Final_Report.pdf). Accessed 7-31-2013.

OHIO

"Neonatal abstinence syndrome (NAS): Treating pregnant women and their newborns." Presented at National Prescription Drug Abuse Summit, Orlando, Florida, April 2-4, 2013. Available at: <http://www.slideshare.net/OPUNITE/nas-treating-pregnantwomensfinal>. Accessed 7-31-2013. This presentation contains the quality improvement efforts undertaken by Nationwide Children's Hospital to improve care of infants exposed to opioids and diagnosed with NAS.

Contacts: **Richard McClead**, Medical Director of Quality Improvement, Nationwide Children's Hospital.

Michele Walsh, Chief, Division of Neonatology, Rainbow Babies and Children's Hospital.

TENNESSEE

Tennessee Department of Health. "Neonatal Abstinence Syndrome (NAS)." Available at: <http://health.state.tn.us/MCH/NAS/>. Accessed 7-31-2013. Website includes weekly surveillance reports on NAS, background materials, and the portal for reporting NAS cases.

Contact: **John Dreyzehner**, Commissioner, Tennessee Department of Health.

VERMONT

Vermont Child Health Improvement Program. "Improving Care for Opioid-exposed Newborns (ICON)." Available at: <http://www.uvm.edu/medicine/vchip/?Page=ICON.html>. Accessed 7-31-2013. Website contains links to Vermont clinical guidelines for the treatment of opioid dependence in pregnancy, "The Care Notebook" for mothers, and educational brochures.

Contacts: **Jerilyn Metayer**, Neonatal Medical & Development Follow-up Nurse Clinician, ICON.

Anne Johnston, Associate Professor, Department of Pediatrics, University of Vermont College of Medicine.

Barbara Cimaglio, Deputy Commissioner of Alcohol & Drug Abuse Programs, Vermont Department of Health.

Jacqueline Corbally, Chief of Treatment, Alcohol & Drug Abuse Programs, Vermont Department of Health.



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Coordinated and Compassionate Care for Families of Babies with Neonatal Abstinence Syndrome

Debra Bercuvitz, MA Dept. of Public Health

Nina Mastropietro, parent

Laura Sternberger, Melrose-Wakefield Hospital



May 12, 2015

Outline

- Introductions
- Overview of Compassionate and Coordinated Care
- Mother's Guidance for Professionals
- Compassionate and Coordinated Care in Action

Structure

- After we each speak you can ask questions
- We will stop after key sections for an opportunity for you to share your expertise
- Please introduce yourself by name, what you do, and if relevant, place of employment

Introduction

- Nina and Laura
- Participants
- Myself

What is NAS?

- Constellation of signs and symptoms of infant neurobehavioral dysregulation that occurs in the immediate neonatal period
- Challenging for babies and all caregivers

- Difficulties with tone and movement--tight muscles and tremors and/or jitteriness. Can lead to difficulties in feeding, which can mean weight loss or failure to thrive.
- Difficulties with state regulation--difficulty maintaining a quiet alert state, which is needed to interact with their caretakers, and to be able to feed and grow. Can have problems going smoothly from sleep to awake states, and often become irritable and cry.
- Difficulties with reactivity to stimuli—can have atypical responses to touch, sound, movement or visual stimulation and can become either over-stimulated and poorly reactive, or “pull down” to avoid the stimulation.
- Problems with autonomic nervous system control—can have gagging, vomiting/diarrhea, color changes, fever, fast breathing or hiccupping, indicating their inability to smoothly regulate their functioning

--Dr. Lauren Jansson

How Common Is It and What Can We Do?

- In 2009, incidence of Neonatal Abstinence Syndrome (NAS) among newborns was 3.39 per 1000 hospital births in the United States (JAMA, 2012).
- MA estimates NAS incidence of 18 infants/ 1000 live births in 2014, five times greater than data reported nationally in 2009. Some hospitals 30-60/1000.
- Can be treated with nonpharmacological and pharmacological care

Skin to skin contact

Breastfeeding

Reduced environmental stimuli (lights, noise, visitors)

Swaddling, pacifier

What is NAS not?

- Not an addiction, not permanent
- **Rx for Danger: Number of Florida babies born addicted to drugs skyrockets**
- "These babies shouldn't have to suffer as a result of their mother's action," [FL Atty Genl] said.
- **Maine Governor Cites 'Troubling Epidemic' of Addicted Babies**

- Open Letter to the Media and Policy Makers Regarding Alarmist and Inaccurate Reporting on Prescription Opioid Use By Pregnant Women

www.advocatesforpregnantwomen.org

What do we want to keep in mind when thinking about coordination and compassion?

- Many different maternal sources of opioid-related NAS that require different supports but not different compassion.
 - Taking medication as prescribed for physical pain
 - Taking medication as part of substance use treatment (methadone, buprenorphine)
 - Taking medication not as prescribed (self-sourcing) for physical (including withdrawal) and/or emotional pain (Rx opioids, heroin, buprenorphine)

Nurse/Resident/OB Provider –Intrapartum MAT

- Need to know on arrival from Pt Chart Clinic
- *Treatment program info contact#
 - Name, Phone #, Dose time, Last Dose
- SS consult (NICU consult AP)
- Who knows about SUD (family/partner)
- Other meds – Allergies
History Depression
- UTOX includes methadone bup.
- Commitment to recovery/ Supports
- Has she had a prenatal consult with anesthesia
- Plan for pain management in labor
- Consult with NICU? Prenatal breastfeeding
- Labor pain management plan
- P.P. pain management plan
 - P.P. birth control plan
 - IP actively using
- UTOX Results
 - HIV
 - Hepatitis B & C
 - STD's
- What drugs does she admit to?
 - Last amount used
- Withdrawal S & S
- Who knows in family (HIPPA)
- Plans? Past tx program
- LMP ?/Guesstimate/ Any PNC/EDC
- 1:1, Calming Influence
- Communicate to clinic (other) pt arrival in L & D
 - MAT Clinic Call for verification
- Ideally have printout from clinic on arrival to L & D

Collaboration for [Opioid-Exposed] Pregnancy, Labor, Birth, and Postpartum Care

(Do in chronological order related to pregnancy)

Remember Consents for Everything ☺

What needs to be done?	When does it need to be done (be specific with wk of pregnancy, at hospital admission, during labor, etc)?	Who has to do it?	What do we need to know to do it?	Who needs to communicate it to me?	What do I need to communicate to others?	To whom do I need to communicate it?
<p>For example:</p> <p>Develop Relationship between OB and Tx provider</p> <p>Prenatal Consult</p> <p>Documentation for DCF</p> <p>Intrapartum and Postpartum Pain Management Plan</p> <p>Plan for Hospital Stay</p> <p>Post Partum Support Plan</p>						

Parents are at the Center With Their Babies

- Consents with full explanation of reason and use
- With the parents and not to the parents
- Begin to build self-efficacy in pregnancy through strong preparation
- Consult with parents as the experts
- Help them to understand their importance to their babies

Overall
Warm Handoffs
Provider education (DCF, EI, medical, Tx)
Collaboration
Data

Potential Policy and Practice Intervention Points for Maternal Substance Use and Substance Exposed Newborns

Birth

- Universal Screening and Targeted Testing
- DCF Referral with Documentation
- Breastfeeding and Attachment Promotion

Preconception

Promote Awareness of Prenatal Substance Use

Screening for Unhealthy Substance Use at all Visits

Reproductive Life Planning

- One Key Question
- LARC

Prescriber Education

Pregnancy

Universal Screening per ACOG

Specialized Treatment Services

Family and Recovery Support

- Peer Mentoring
- EIPP
- MHVI
- Specialized Home Visiting

Consistent Messaging

- DCF
- Breastfeeding
- Tobacco Cessation
- EI
- Home Visiting

Parent Education

- Pregnancy
- DCF
- Hospital

Prenatal Consults

Postpartum or Neonatal/Infancy

Priority entry into (specialized) treatment

Early Intervention

- Increase capacity for family interventions
- Track EI referrals, assessment, eligibility, services
- Enhanced linkages

Family and Recovery Support

- Peer Mentoring
- EI
- MHVI
- Specialized Home Visiting

DCF

- MAPP training on SEN, working with birth family
- Increased visitation with babies
- NICU visitation as possible

Parenthood and Childhood

Clinical and Peer Parenting and Recovery Services

Early Intervention

Special Education and Other Services

Targeted Substance Use Prevention

Experiences of Mothers of Infants with Neonatal Abstinence Syndrome in the Neonatal Intensive Care Unit

Lisa M. Cleveland and Rebecca Bonugli

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Keywords

substance addiction
mothering
neonatal intensive care unit
neonatal abstinence syndrome

ABSTRACT

Objective: To describe the experiences of mothers of infants with neonatal abstinence syndrome (NAS) in the neonatal intensive care unit (NICU).

Design: Qualitative description.

Setting: We recruited participants from community-based, out-patient, addiction treatment facilities in a large urban city in the southwestern region of the United States.

Participants: A convenience sample of 15 Hispanic, substance addicted mothers of infants with NAS participated.

Methods: We conducted semistructured, individual, interviews and analyzed the data using qualitative content analysis. First, we analyzed the data independently and then discussed the themes until a consensus was reached.

Results: We identified four themes: (a) understanding addiction, (b) watching the infant withdraw, (c) judging, and (d) trusting the nurses. The participants felt there was a lack of understanding concerning addiction that was particularly noted when interacting with the nurses. They shared their feelings of guilt and shame when observing their infants withdrawing. The participants felt judged by the nurses for having used illicit drugs during pregnancy. Feeling judged interfered with the participants' ability to trust the nurses.

Conclusion: These findings provide nurses with a better understanding of the experiences of mothers who have addiction problems and may lead to more customized nursing care for this high-risk population of mothers and their infants.

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Substance use during pregnancy can lead to poor neonatal outcomes by increasing the risk of prematurity, low birth weight, and neonatal abstinence syndrome (NAS) (National Institute on Drug Abuse, 2011). Infants with NAS present with symptoms of withdrawal such as extreme irritability, inconsolable crying, vomiting, diarrhea, and even seizures (Hudak & Tan, 2012). These infants frequently experience lengthy hospital stays (Patrick et al., 2012) and typically require a significant amount of nursing care (Fraser, Barnes, Biggs, & Kain, 2007; Macguire, Webb, Passmore, & Cline, 2012; Murphy-Oikonen, Brownlee, Montelpare, & Gerlach, 2010; Raeside, 2003). Nurses face a variety of challenges when providing care for substance addicted women and their infants. Care of these infants is time-consuming and usually requires a significant amount of patience. Nurses also report that interacting with mothers

who are addicted can be a source of work-related stress (Fraser et al., 2007; Macguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003) as these women often have substantial comorbidities such as mental illness, poverty, and a history of trauma (Pajulo et al., 2001; Powis, Gossop, Bury, Payne, & Griffiths, 2000). A better understanding of the experiences of these women could lead to improved care for this high-risk population of mothers and infants.

To our knowledge only one study exists in which the authors explored the experiences of mothers of infants with NAS (Cleveland & Gill, 2013). The authors presented a secondary analysis of interviews from five substance addicted mothers who participated in a larger study on the experiences of Mexican-American mothers in the neonatal intensive care unit (NICU) (Cleveland & Horner,

2012a, 2012b). Findings indicated that the women felt judged by the nursing staff yet longed to make a personal connection with the nurses. Additionally, the women voiced concerns over inconsistencies in the use of instruments to measure NAS symptoms in their infants. They also felt a need to assert themselves as mothers. Although the findings presented in the Cleveland and Gill (2013) article are useful, the sample size was small and may not be representative. A more complete understanding of the mothers' experiences is needed.

Background and Significance

It is estimated that 16% of pregnant teens and 7% of pregnant women age 18 to 25 use illicit substances during pregnancy (Substance Abuse and Mental Health Administration [SAMHSA], 2011). Further, approximately 60% to 80% of all infants exposed in-utero to opioids such as heroin and methadone will develop NAS (Doberczak, Kandall, & Friedmann, 1993). In the United States, between the year 2000 and 2009, maternal opioid use during pregnancy increased fivefold (Patrick et al., 2012). This dramatic increase in incidences is likely related to the increased use of prescription opioid pain killers (Patrick et al., 2012). It is not surprising then that during this same time period the number of infants diagnosed with NAS increased threefold. The cost of caring for these infants has likewise increased over the past decade from an estimated \$190 million per year to \$720 million per year (Patrick et al., 2012).

In addition to financial cost, providing nursing care for infants with NAS can be challenging (Fraser et al., 2007; Macguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003). A few researchers have described the experiences of nurses who care for infants with NAS (Fraser et al., 2007; Macguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003). In these studies, nurses shared their commitment to the infants and their desire to provide quality care. However, some NICU nurses believed that this level of nursing care did not require specialized skills and could be provided somewhere other than in a NICU. They felt that caring for infants with NAS was not what they had anticipated when they became NICU nurses. Further, they described the high-pitched cries of the infants and the frustration they felt when trying to provide comfort to infants who were often inconsolable (Murphy-Oikonen et al., 2010). The nurses expressed concern about the mothers' ability to cope with an irritable, crying infant following discharge and worried about

Infants with neonatal abstinence syndrome frequently experience lengthy hospital stays and typically require a significant amount of nursing care.

the infant's safety (Macguire et al., 2012; Murphy-Oikonen et al., 2010). They also worried about the stability of the infant's home upon discharge from the NICU (Macguire et al., 2012; Murphy-Oikonen et al., 2010).

Nurses claimed that interacting with families with addicted members was stressful for them (Macguire et al., 2012) and acknowledged negatively judging mothers because they used illicit drugs (Fraser et al., 2007; Macguire et al., 2012). Further, the nurses described what they perceived as the defensive attitudes of the mothers when they visited their infants in the NICU. Several nurses recalled being verbally attacked by mothers and their family members. They also reported altercations between families in the unit, and one nurse even remembered a family member threatening her with violence (Macguire Webb, Passmore, & Cline, 2012). Lastly, some nurses described feeling that they lacked the necessary education in mental health and substance addiction to provide optimal care for families experiencing addiction (Fraser et al., 2007; Raeside, 2003).

In the one published article focused on the experiences of mothers of infants with NAS, Cleveland and Gill (2013) conducted a secondary analysis of data from a larger qualitative study to describe the hospital experiences of mothers of infants with NAS. The authors analyzed the data from these women separately because their experiences were uniquely different from the other NICU mothers who had participated in the study. They identified four primary themes: (a) "try not to judge," (b) "scoring the baby," (c) "share with me," and (d) "I'm the mother here!" All five of the mothers described events where they felt they had been negatively judged and believed that the nurses were unable to see past their drug addiction and recognize any of their positive qualities. At times, the mothers' sense of being judged kept them from visiting their infants in the NICU. The mothers shared their thoughts on the use of neonatal abstinence scales to "score" their infants describing the use of these instruments as highly subjective as the nurses scored the infants with great variability. The mothers valued the nurses' ability to communicate

on a personal level and "share" with them as this made the mothers feel more welcome in the NICU. Finally, the mothers described a desire to assert themselves and assume the mothering role. They expressed frustration and resentment when they perceived that the nurses were taking over the infant's care and not allowing them to participate.

In light of the recent increase in maternal opioid use during pregnancy and the associated diagnosis of NAS in their infants, further research on this topic is needed. A better understanding of the experiences of mothers of infants with NAS may provide insight for nurses who care for this vulnerable population. Therefore, the purpose of this study was to explore the NICU experiences of mothers of infants with NAS.

Methods

We used a qualitative, descriptive approach to conduct this study. We chose this method because it allows the "straight description of phenomena" and enables the researcher to stay close to the data provided by the study participants (Sandelowski, 2000, p. 334). We obtained Institutional Review Board approval prior to the onset of data collection. Our inclusion criteria for participation were women who were (a) at least age 18 years, (b) English speaking, and (c) the mothers of infants born with NAS. Based on the findings of a previous study conducted by the primary investigator, we decided not to exclude participants based on the length of time that had passed since discharge of the infant from the hospital (Cleveland & Horner, 2012a). In this prior research, it was discovered that the passage of time did not seem to alter mothers' recollections of their experiences and may actually have allowed time to process events. Each participant provided consent to participate after the purpose of the study was thoroughly explained. We continued to enroll women until data saturation was achieved, at which time the participants shared no new information and the data became redundant (Polit & Beck, 2012).

We recruited participants from two different community-based, out-patient, addiction treatment facilities in a large urban city in the southwestern region of the United States. One of these facilities houses the city's methadone treatment program. After obtaining permission from the facilities' administration, we distributed flyers about

the study that contained our contact information. We also conducted a staff in-service at each facility to provide information about the study purpose and the inclusion criteria. Women who wanted to participate in the study contacted us directly.

We collected demographic data using a demographics questionnaire to provide a more complete understanding of the sample characteristics. Semistructured, individual, interviews were conducted in a private location chosen by the participant. The following open-ended questions were used to guide the interviews: (a) Tell me about your baby, (b) Tell me what it was like when your baby was experiencing withdrawal, (c) What things did you do to take care of your baby during this time? (d) What was your greatest concern for your baby? (e) Tell me about your relationship with the NICU staff (physicians, nurses, etc.) when your baby was in the hospital, (f) If you could offer any advice to the staff about caring for mothers and infants with substance addictions, what might you say to them? (g) What advice might you offer to other mothers like yourself? and (h) Is there anything you would like to share with me that I haven't already asked about? The same researcher conducted all of the interviews, and each participant was interviewed once. Five of the interviews were conducted in the participants' homes, two in a small classroom in one of the out-patient facilities, and eight in a private office or small classroom at the out-patient facility where the methadone clinic was located. The interviews were audio-recorded and ranged in length from 50 to 90 minutes. Probe questions were added when needed to ensure richness of data (Polit & Beck, 2012). A professional, medical transcription service was used to transcribe all interviews verbatim.

We analyzed the data using qualitative content analysis thus allowing themes to emerge from the data with the goal of answering the research question (Hsieh & Shannon, 2005). We began this process with line-by-line analysis of the transcribed interviews. We then broke the data down into smaller units and assigned labels or codes based on the content they represented. Following this, we grouped the coded data together according to concepts to form themes (Polit & Beck, 2012). We adhered to this process to first analyze the data independent of one another. After doing so, we compared themes and discussed them until we reached a consensus. We followed this data analysis process to improve the rigor

and trustworthiness of our study findings (Fade, 2003).

Sample

We used purposive sampling to recruit a convenience sample of 15 mothers of infants with NAS. The women ranged in age from 22 to 40 years (mean = 28 years), and all self-identified as Hispanic although participation was open to women of all ethnicities. The ethnicity of our sample is likely reflective of the ethnic makeup (greater than 60% Hispanic) of the city where this study was conducted (U.S. Department of Commerce, 2013a). Eight of the women had less than a high school education, four had a high school diploma or equivalent, and three had education beyond the high school level, but none had a college degree. Three of the women were employed. Ten women were single, three were married, one was divorced, and one was widowed.

Although we did not set out to collect data specifically related to the mothers' illicit drug use or mental health, the women volunteered much of this information during their interviews. We feel this information is important to include as these aspects of the women's lives may impact their perceptions of their NICU experience. For almost all of the women, the use of illicit drugs began early at an average age of 14 to 15 years, and the drugs were most often introduced by an older and trusted individual; commonly a family member or boyfriend. All but two of the women reported concerns related to mental health. Among the participants, bipolar disorder was the most common self-reported psychiatric diagnosis followed by depression, anxiety disorders, and attention deficit disorder. Further, most of the women had experienced personal violence sometime in their life whether it was childhood sexual abuse, intimate partner violence, or physical and/or sexual assault. Several of the women had been incarcerated at least once for drug possession and/or prostitution. At the time of interview, 13 of the women were enrolled in a methadone maintenance program. Fourteen of the women had been addicted to heroin with one having been initially addicted to prescription pain killers before she turned to heroin. The only woman not addicted to opioids had been addicted to cocaine at the time of her delivery but stated she was no longer using cocaine when interviewed.

We interviewed most of the women 3 days to 6 months following discharge of their infant from the

hospital although one participant's child had been discharged 11 years prior to the study. Her interview data did not differ from that of the other women. The women had from one to seven children (Mean = 3, total = 51), and three had given birth to multiple infants with NAS (Table 1). The infants' average length of hospital stay was 52 days with a range of 14 to 270 days. Two of the women did not have custody of their infants at the time of interview. One woman's child was in the custody of a family member, and the other woman had a child in foster care. It is also important to note that seven of the women had older children who had been placed for adoption; most having been adopted by a family member. The mothers reported that all of the infants were healthy with four of the mothers stating that their children had suspected or confirmed developmental delays or learning disabilities. Lastly, though we did not specifically ask where the mothers delivered, many of the women revealed this information through the process of their interview. The women had delivered in at least five different hospitals within the same city.

Results

Our findings revealed four themes that describe the NICU experiences of mothers of infants with NAS: (a) understanding addiction, (b) watching the infant withdraw, (c) judging, and (d) trusting the nurses.

Understanding Addiction

Throughout the interviews, the women spoke in great detail about their addictions. They discussed their lack of understanding related to the process of addiction even after having become addicted. Moreover, they felt that the nurses they encountered during their infant's hospital stay lacked necessary education about substance addiction and felt this affected the nurses' ability to provide care for them and their infants.

Mothers. Although, all of the women either had family members or significant others who were addicted, they still admitted they had little knowledge of how quickly addiction could occur and the power it could have over their lives. One woman said, "Until it happened to me, I didn't really think you could get addicted to a drug like that, and it's ugly." Interestingly, all of the women recalled receiving some type of drug use prevention education during their time in public school, but most said they paid little attention to it as they felt it had limited relevance to them. One woman said

Table 1: Demographic Characteristics of the 15 Participants

			Work	Number		Time Since	Infant	Other
	Age	Marital Status	Education Level	Outside Home	of Children	NICU Stay	Infant's Health Problems	Children in NICU
1	34	Married	High school diploma	No	5	2 weeks	5 ½ months	Developmental delay
2	24	Single	10 th grade	No	2	2 ½ weeks	3 days	No
3	24	Married	GED	No	3	2 weeks	2 years	Speech delay Yes
4	25	Single	9 th grade	No	4	6 weeks	5 months-Foster care	No
5	22	Single	7 th grade	Yes	1	2 ½ weeks	4 ½ months	No
6	22	Single	High school diploma	No	3	9 weeks	4 months	No
7	40	Single	11 th grade	No	3	2 weeks	11 years	ADHD/Dyslexia No
8	24	Single	Some college	No	1	5 weeks	4 weeks	No
9	28	Widow	11 th grade	Yes	7	5 weeks	3 weeks	No Yes
10	27	Single	9 th grade	No	2	2 weeks	1 ½ weeks	No
11	33	Married	9 th grade	No	7	3 weeks	2 months	No Yes
12	32	Divorced	11 th grade	Yes	3	4 weeks	1 month Cared for by mother-in-law	No
13	28	Single	High School	Yes	5	16 weeks	1 year	No
14	31	Single	Trade school	No	3	6 weeks	13 months	No
15	24	Engaged	10 th grade	No	2	5 weeks	17 months	No

Note. NICU = neonatal intensive care unit; GED = general educational development certificate; ADHD = attention-deficit/hyperactivity disorder.

of the drug education she received in school, "It was kind of a joke."

It is also important to mention that even in families where drug use was common, few of the women ever recalled having conversations about drug use with their family members, not even with their parents. Several women recalled that drugs were just something they never discussed. One woman with an extensive family history of substance

addiction provided details about how her use of prescription pain killers, following an accident, eventually led to her heroin addiction. She explained how she had always avoided her family members who were using drugs because she saw the consequences addiction had on their lives. Now on methadone maintenance, the woman described how she felt when she entered the methadone clinic one morning for dosing and found herself standing in line right next to her

cousin who was a known long-time heroin user. She shared the irony of her story, "I just never thought I would end up here!"

The women discussed the many aspects of their addiction. Several talked about personal characteristics they felt contributed to their drug use. One mother shared:

We don't know how to cope with reality, and so we're scared of it. When we relapse...just to go back to the comfort of numbing that, you know? And that's one of my things, like I'm scared of reality. I'm actually used to numbing it whether it's methadone or something else. It's like...that's one of the things I pray for...give me the strength to cope with this reality.

Another woman discussed how she was unable to express herself emotionally and felt that this was a contributing factor in her drug addiction. All of the women described the consequences of using drugs and their fear of relapse. One mother explained:

It takes everything away from you. It takes your kids away. It's taken so much away from me that I don't know how I still relapse...how I still give it a chance. I guess I'm still working on it. Like I said, we lose family, we lose everything, even the clothes we have on our backs sometimes. We lose everything and we still fall. You know, like why relapse? Nothing good comes out of it.

Lastly, one woman, who had achieved sobriety, shared what she wished she could tell her infant's father. She claimed to still love him but had broken all ties with him because he continued to use drugs, "He's suffering, and I know how it feels. And if only he can know that it feels this good to actually be sober and be okay with yourself. It's a lot of work, though. It's a lot of work."

Nurses. The mothers felt that few of the nurses they encountered truly understood addiction and that this contributed to the way the nurses interacted with them. One mother stated, "I don't think [the nurses] really understood. They just saw the baby and what I did...which is understandable. Like, they just saw a heroin addict and that's it." Another woman felt that perhaps the nurses lacked

the necessary education to understand the aspects of addiction that affected the mother:

Maybe [the nurses] lack the education, you know what I mean? Um...I think they knew a lot about what the baby goes through as far as withdrawal and withdrawing, but what it takes to get to that point, like why this baby was withdrawing? Okay, you know that this mother used. Why was she using? You don't know that.

One woman shared her thoughts on how the nurses might be more helpful in their interactions with mothers with addictions. When asked if there was any advice she might like to share with nurses who care for infants with NAS she responded:

I would just tell [the nurses] to take it easy [on the mother]. You know, after being addicted, I realized that this is really a disease. There are some who abuse, but if you're using while you're pregnant, you have a problem; a big problem...and you need help. You obviously don't care about yourself, about anything, except the drug. Make it a little bit easier on that mother if she's showing initiative...if she's taking the time to be there. If she loves her child, you can see it and you can feel it. If it's obvious that she's there for the baby then embrace it; make it easier. You don't know what her circumstances are. You don't know what she's been through or how hard her life has been. You don't know what she was feeling when she was pregnant...if she was being abused, if she was poor. Whatever the reason she was using while she was pregnant...you just don't know. So, try to make it easier for her.

Another woman shared:

I think they should get all the nurses together and have a meeting to talk about us, about how we got hooked and about how hard it is for us to see the babies withdraw. [Tell them] how we would want them to help us, and not just point fingers and say "You're on drugs and that's why your baby is here." For some of us, it's just something that happened and we wish we could change that, but we can't.

Watching the Infant Withdraw

The women described the shame and guilt they felt when they witnessed their infant experiencing withdrawal symptoms. They talked about the inconsolable crying, tremors, and the sense of helplessness in their inability to relieve their infant's distress. One mother shared about her infant, "He was just so jittery, you couldn't touch him . . . there was no consoling him. He would just cry." Another expressed her feelings of helplessness, "When he would cry, sometimes I would cry with him because he would cry for hours, you know, and all I could do is just hold him and rock him." Additionally, the women talked about the busy nature of the NICU and how they often felt that there was an insufficient number of nurses available to provide the demanding care infants with NAS require. They also observed the nurses' frustration in attempting to care for their inconsolable infants and at times felt that the nurses took this frustration out on the mothers.

All of the women expressed guilt for what their infants were experiencing. One stated about her daughter, "I know it's my fault, but she shouldn't have to suffer because of things I chose to do." Another talked about not wanting to visit the NICU because she couldn't face the guilt and pain she felt when seeing her infant's withdrawal symptoms. However, most of the women attempted to cope with their feelings of guilt by being there for their infant. One woman said, "As much as I felt guilt for what I did, I wasn't going to leave my child. I couldn't." Another recalled:

I needed him, and he needed me. I needed him because I felt . . . I did bad. I hurt him, you know? If it wasn't for my drug use, my stupidity, he wouldn't be going through this. I put him through this. So, I needed to be there because he needed my help. He's just an angel. He's a baby. He doesn't understand, so I had to be there. I put him in that situation. And I . . . myself . . . had to help him . . . nobody else but me.

Judging

The women described feeling negatively judged by the nursing staff because of their history of illicit drug use. One mother said, "I felt judged. I felt like the nurses thought of me as a drug user and that was my whole life story." Another woman shared, "I felt judged and ridiculed all at once." At times, this sense of being judged served as a deterrent to mothers visiting their infants in the NICU.

One mother told a story of overhearing two nurses discussing the care of her infant:

[The nurse] was like, "You're going to have a lot of problems with that little baby because he's real jumpy and jittery. His muscles are locking up because of his junkie mom." I didn't want to visit. I would call before and if [that nurse] was there, I wouldn't even go. Yea, and [Child Protective Services] was like, well you're not even acting like you care about him. You're out using still. And it wasn't that I was out using, it was that I didn't want to be around that nurse because she made me so uncomfortable.

Another woman expressed her anger upon feeling negatively judged by one of the nurses. She said, "I felt like turning around and saying to her, 'Do you know me? Do you really know me?'" One mother went on to explain how she felt the nurses were overstepping their role by judging addicted women:

That's why they have social workers. Social workers talk to [the mothers] while we're there. They have to ask you about your plans after you take your baby home. The nurses don't. The nurses have to take care of the baby while they're there for their shift and then they're gone. Then the next shift comes in and takes care of the baby and then they're gone.

Some of the women had a slightly different perspective on feeling judged. Because of their drug use, several mothers stated they expected to be judged and felt they deserved it. One mother said, "That's just the way people are, they have to judge." Another stated, "I expected it because I almost killed [my baby]." Further, several of the mothers felt that their only priority was to ensure their infant received the best care possible. They stated they were fine with being negatively judged as long as their infant received good nursing care and was treated with respect. One mother shared:

I did notice that [the nurses] were a lot nicer and a lot more social with [the nonaddicted NICU mothers], but I didn't have a problem with it. As long as they did what they were supposed to do as far as [my baby's] treatment and him being okay. I didn't have a problem with it.

Lastly, the mothers told stories of entering the NICU for the first time and expecting to be judged and their relief when this did not happen. The women discussed how much this meant to them and how it made them feel comfortable when they came to visit their infant. One mother recalled a conversation with a NICU nurse who said to her, "I don't know what you've been through, girl, so I'm not gonna sit here and judge you." Another said of her infant's stay in the NICU:

It was a great experience. They understood. They didn't make me feel like an outcast. They made me feel very comfortable. I was able to talk to them about it and . . . I didn't have to hide [my drug history]. I had a good relationship with the nurses.

Further, another woman shared how she never missed a NICU reunion and a chance to visit the nurses she felt had helped her and her son. She expressed great gratitude for their care.

Trusting the Nurses

Trust was a difficult issue for the women, and several described events in the NICU where they felt they were unable to trust the nurses. This left the mothers concerned and feeling vulnerable particularly when they had to leave the NICU and go home. One woman described how she had to concentrate on being "submissive" when she was visiting the NICU because she did not want to anger the nurses as she felt this might jeopardize her son's care when she was unable to be present. She recalled a conversation she had with her infant's father in the NICU where she warned him to do the same:

You know what? You need to be careful with how you say things, your tone of voice—everything. Because we're gonna leave and he's gonna cry and they're gonna leave him crying because they're gonna be like, "You know what? His parents are jerks!" I said, "I don't want that. So just hold it in and you can tell me all about it when we leave. But don't say anything!"

The women tried to cope with their lack of trust. Usually this involved the mothers being present in the NICU as much as possible. One woman described how she ensured her infant received good care:

Mothers described feeling judged by the nurses; however, some stated they expected to be judged and even felt as though they deserved it.

I would make sure I was there all day. I would make sure that I was there the entire day. It was hard because I was exhausted. I mean, I wasn't able to rest like, you know, you're supposed to rest during this time. And I was constantly going and going and going, and driving myself.

Still, not all of the mothers were able to spend this much time with their infants leaving them concerned about their infants' well-being when they were away.

Several of the mothers recalled occurrences with the nurses that further contributed to their inability to trust. One woman had experienced multiple conflicts with a particular nurse on the unit and eventually reported the nurse to the nurse manager. The mother was assured by the nurse manager that this nurse would no longer be providing care for her infant. Although the mother expressed relief she continued to worry:

I didn't have to see [that nurse] no more or worry that she would come in to . . . be mean to [my baby] because I went and told on her. You know, and then I was starting to worry. I told my mom, "I'm worried now that she's still his nurse. She's going to be ugly with him because I told the head nurse."

Another woman discussed how she had lost all trust in the nurses after discovering that they had documented information for her Child Protective Services caseworker to read. She claimed the information was untrue and felt she was wrongly accused of saying something she would never have said.

Discussion

The themes we identified offer an exploration into the NICU experiences of mothers of infants with NAS. Further, they add to the existing literature as well as shed new light on the complex nature of addiction during pregnancy. As discussed, our study sample was rather unique in that all 15 women were Hispanic. This is interesting because recent research findings indicate that the use of illicit substances in pregnancy is highest in non-Hispanic

whites followed by Hispanics and non-Hispanic Blacks (Muhuri & Gfroerer, 2009). As discussed, the over-representation of Hispanic women in our sample is likely a result of the ethnic makeup of the city where this study was conducted. Further, similar to recent national statistics which indicate that 25% of the U.S.' Hispanic population lives in poverty (U.S. Department of Commerce, 2013b), all of our participants had experienced poverty at some time during their life, and most were living in impoverished areas of the city at the time of interview. Poverty and residing in disadvantaged neighborhoods are factors commonly associated with an increased use of illicit substances (Boardman, Finch, Ellison, Williams, & Jackson, 2001). Therefore, the use of illicit substances in this study sample may be more related to the women's socioeconomic status than to their ethnicity.

A past history of trauma was also common for the women in this study as many had endured personal violence. This finding is consistent with studies indicating that the majority of women who abuse substances have experienced sexual and/or physical abuse (Quimette, Kimerling, Shaw, & Moos, 2000). Further, many of this study's participants had experienced separation from significant others particularly the loss of their children as a result of their addiction. This is noteworthy because traumatic experiences are known to result in negative health outcomes including substance abuse and psychiatric comorbidities (Druss, Rohrbaugh, Levinson, & Rosenheck, 2001). Therefore, as one participant shared, illicit substances were used to temporarily numb the psychological pain associated with these past traumatic events. This further highlights the importance of developing gender specific trauma-informed recovery programs that meet the multiple needs of women.

The participants' general lack of understanding about their addiction and its consequences are interesting findings. This is particularly true in the context of the women's significant family histories of addiction. The women's claims that few had ever discussed substance addiction with their parents or other family members are concerning and require further examination. Parents and/or primary caretakers are a child's first source of education and have an impact on the development of attitudes toward certain behaviors (Harvard Family Research Project, 2006); therefore, the importance of open dialogue about drug use within families is critical (National Crime Prevention Council, 2013).

Also interesting to note, all of the participants had received some type of drug use prevention education in school, but none felt it had been particularly useful. In the United States, the war on drugs involves significantly more federal dollars being spent on law enforcement than are spent on drug use prevention (National Drug Control Strategy, 2012). Perhaps a shift in funding to better support prevention education would be a more effective approach. Further, efforts are needed to better tailor educational programs to meet the cultural and population specific needs of learners.

In this study, we identified nurses' lack of knowledge related to addiction, and this was accompanied by negative experiences for the majority of the mothers. This is consistent with prior research findings. Raeside (2003) discovered that maternal/child nurses had a limited knowledge base related to addiction and lacked the psychiatric/mental health and substance addiction education needed to provide optimal nursing care in the context of maternal substance addiction. This may contribute to a strained nurse/mother relationship and has the potential to compromise care. Therefore, it is essential for maternal/child nurses to receive the necessary education in mental health and substance use disorders so they might better understand women with addictions and customize nursing care to their complex needs. This education could be offered through a variety of methods that would allow easy access for nurses. One suggestion would be to offer an online educational unit that nurses could complete at their own pace. In the future, this educational opportunity might be made a mandatory activity for the maintenance of various maternal/child or neonatal nursing certifications.

Watching the infant withdraw has not previously been discussed in the literature. This theme is interlaced with the mothers' feelings of guilt for having exposed their infants to drugs as well as a sense of helplessness when the mothers were unable to provide comfort for their infants. One mother described not wanting to visit her infant because of the distress it caused her to see him in pain. However, several other women explained how they felt they were responsible for their infant's suffering and, therefore, had to be present to provide comfort. For these women, there was a certain degree of ownership for what had happened and a desire to somehow make it right. It might be helpful for nurses to assist the mothers of infants with NAS by demonstrating comforting techniques to soothe their irritable infants. An

intervention such as this may encourage mothers who visit infrequently to be more present and would also provide the engaged mothers with tools to help them successfully meet their infant's needs and minimize their own frustrations.

Feeling judged by the nursing staff is a previously reported research finding (Cleveland & Gill, 2013) yet it deserves further exploration that was provided by this study. Health care provider attitudes toward mothers with substance addictions are often value laden and may serve as a barrier to the development of a therapeutic relationship (Fraser, Barnes, Biggs, & Kain, 2007; Macguire et al., 2012; Murphy-Oikonen et al., 2010; Raeside, 2003). Nurses' inability to recognize addiction as a disease may further contribute to judgmental attitudes toward women with addictions creating an additional barrier. In this study, mothers described feeling judged; however, we found that some expected to be judged and even felt as though they deserved it. This finding may imply an underlying sense of guilt and low self-esteem that is a common finding in substance addicted individuals (Brown, 2006; Ehrmin, 2001; Merrit, 1997). However, these feelings may create additional difficulties for a mother who is coping with addiction while attempting to establish a relationship with her infant.

Another unique finding of this study is the reaction of the women when they realized they were not going to be judged by the nurses. As most expected judgment, this was a welcome surprise and helped the mothers feel more at ease during visits. With any NICU mother, efforts to encourage maternal involvement should be supported whenever possible and appropriate. Therefore, it might be beneficial for nurses to participate in self-reflection activities focused on their perceptions of women addicted to substances. In doing so, a better sense of self-awareness may be possible, and perhaps judging behaviors can be minimized. As nurses, our goal is to provide supportive care in a nonjudgmental manner, and thus judging is not conducive to this common goal. Further, additional research to explore the experiences of nurses who care for women with addictions and their infants is needed, and we are currently in the process of conducting qualitative interviews with nurses to gain a better insight into their experiences.

Mothers having difficulty trusting the care of the infant to another has been described in previous

Maternal/child nurses need specialized education in mental health and substance use disorders to better understand women with addictions and customize their nursing care.

studies of NICU mothers (Cleveland, 2008; Cleveland & Horner, 2012b; Higgins & Dullow, 2003; Hurst, 2001a, 2001b). However, in this study issues of trust may have been further complicated by the mothers' history of substance addiction particularly when mental illness and a past history of abuse and victimization were involved. In previous studies, researchers found that mothers develop strategies for dealing with this lack of trust, and these strategies often included frequent telephone calls to the unit, being present at the infant's bedside as much as possible, and avoiding conflict with the nursery staff (Cleveland & Horner, 2012b). All of these findings are consistent with the findings of this study; however, this lack of trust was particularly compounded by the mothers' concerns that their crying, irritable infants would not receive the care they needed and by a fear of speaking up about these concerns. The threat of Child Protective Services involvement was also an ever-present worry.

Limitations of the Study

As with any research, our study has limitations. First, our sample consisted of all Hispanic women. This is likely the result of our recruiting participants from the southwestern region of the United States; however, this lack of ethnic variation may have affected our results and must be considered. Further, all of the women who participated were in addiction recovery at the time of interview. This sample characteristic may have skewed our findings in several ways. First, it is possible that women who successfully achieve recovery possess characteristics that make them uniquely different than women who continue to use illicit substances. Or, perhaps our participants, having gone through the process of recovery, were successful in reaching a certain degree of self-awareness and perspective that women who are still using illicit drugs have not yet achieved. Due to ethical concerns related to interviewing women who are custodial parents and are actively using drugs, the feasibility of these women participating in a study such as this one may not be realistic; however, one must consider the possibility that these women may possess characteristics that make them different from our sample.

Conclusion

Substance use in pregnancy is a complex issue that is often compounded by comorbidities such as mental illness, poverty, and violence. Infants born with NAS require a significant amount of nursing time and care. Due to the many factors that surround substance addiction, it may be challenging for nurses to provide therapeutic care for these high-risk mothers and infants. The findings presented in this article provide nurses with a more complete understanding of the experiences of mothers with addictions. This in turn may assist nurses to customize care that will better support these women in their transition to motherhood and may enhance parenting outcomes for this population.

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Coordinated and Compassionate Care

Maternal Substance Use Disorders and
Substance Exposed Newborns

May 12, 2015

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Coordinated care *is* compassionate care.

Coordinated Care Providers Share:

A common language, theoretical understanding of client population and standards of empirically based best practices.
(Universal Training.)

A mutual investment in the relationship with clients, training, data collection, resource sharing/management, development of legislation and policies. (Stronger Together.)

Care providers include anyone in the care continuum birth-five.

- Receptionists, intake workers, ER personnel, law enforcement officers, EMTs.
- Practitioners in schools, clinics, WIC offices, Healthy Families, lactation specialists, birth educators, dulas.
- Other families (peers) or family members.
- VNA, EI, DCF, recovery specialists, pediatricians, coaches.

A universal knowledge base for Coordinated Care Providers should include an understanding of:

- Disease Model of Substance Use Disorders.
- Dual Diagnosis.
- Trauma Informed Care.
- Screening tools and referral to accessible resources.
- Protective factors.
- Importance of peer support for client. (Stronger Together.)
- Importance of peer support/guidance/supervision/training for caregiver. (Stronger Together.)

Trauma Informed Care: a universal practice approach.

- TIC Services are based on an understanding of the vulnerabilities, adaptive styles and triggers of trauma survivors. Some traditional service delivery approaches may worsen symptoms.
- Patients with chronic SUD, dual diagnosis and trauma histories often have trouble with affect regulation, trust, self soothing, organization and focus.
- Key principles of TIC emphasize a non judgmental, empowering, transparent, strengths based and welcoming continuum of care.
- TIC principles address potential for caregiver secondary trauma.

Risk Factors associated with SUDs:

- Prior history of Substance Use Disorder, older child with fetal alcohol syndrome or neonatal abstinence syndrome.
- History of Trauma (physical, verbal and/or sexual abuse, neglect and intimate partner violence.)
- Mental illness.
- Chronic medical illness, especially autoimmune illnesses.
- Financial and housing instability.
- Legal involvement.

Protective Factors (for mother and baby.)

- Social support, education and mutual support.
- Concrete services (housing, food, healthcare, financial assistance, transportation.)
- Early treatment interventions.
- Consistency and tight collaboration throughout the continuum of caregivers for mother and infant.
- Breast Feeding.
- Rooming in/skin to skin.

Our practice at Melrose Wakefield Hospital, a work in progress.

- Between 2009-2012 our numbers of Substance Exposed Newborns born per 1000 deliveries became the third highest in the state. (MWH 69/1000; State average 17/1000.)
- In 2011, Dr. Brian O'Connor, a MWH OB, founded Middlesex Recovery, a full service buprenorphine clinic.
- In 2011 MWH established The Supported Birth Program, a community outreach program for women with SUDs and SENs.
- In 2011 MWH joined the Vermont Oxford Network, an international workgroup of neonatal providers, to research best practices for NAS.
- In 2011 began training and support to all hospital staff.
- In 2014 families began to round weekly with VNA, EI, DCF before discharge.
- In 2015 established a maternal SUD and SEN Collaborative.

The hospital prenatal visit:

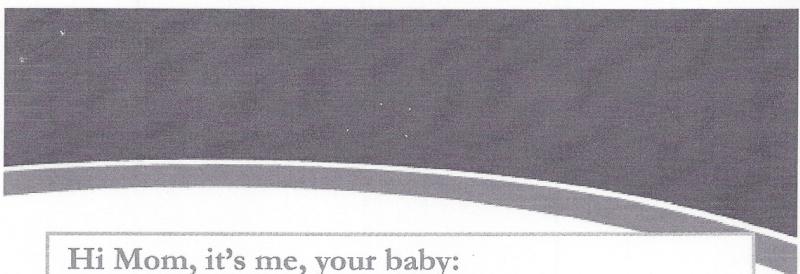
- Can happen at any time before or during the pregnancy.
- Can be initiated by any caregiver.
- Will include: explanation of NAS, policies around medical five day hold on baby's discharge, DCF, breastfeeding, anesthesia, neonatology, tour of facility, support around interactions with family.
- Will most often lead to referrals and introductions to other providers and peer support.
- Hospital occasionally able to provide support through early childhood years.

Important Information for Families:

- A positive urine toxicology screen does NOT ALWAYS mean child will be removed from custody of parent.
- DCF will be called **anytime** an infant is born exposed to an illicit or addictive substance, even if prescribed. DCF will assess the situation and decide whether to screen out.
- Breast feeding is almost always encouraged/supported except when UTS is positive for illicit substances at birth, no HIV test within 30 days before birth, Hep C+ with high viral load.
- Infant will remain in the hospital for at least 5 days to observe for NAS. Mothers may room in during the 5 day hold if space permits. Infant will be transferred to Special Care Nursery if NAS symptoms occur. (3 scores of 8 or more.) All SENs will be referred to VNA and EI regardless of length of stay.

Patients can help the process.

- Be honest; help will be provided.
- Call hospital social worker, set up meeting and/or attend mother's group. (Often held in Methadone or Buprenorphine provider clinics.) Ask for support.
- Read information about NAS provided in OB offices. Ask questions.
- Sign "full information" releases to DCF for Methadone, Buprenorphine and OB and mental health clinics. The initial assessment will go faster.



Hi Mom, it's me, your baby:

I can't wait to finally meet you and see your face. There are some important things I want to share with you about my upcoming arrival at Melrose-Wakefield Hospital. There is a possibility I might experience a form of withdrawal called neonatal abstinence syndrome or NAS. The symptoms can make me uncomfortable and might not appear right away. The doctors and nurses know just what to look for and will keep a close eye on me for five days. I don't want you to worry if I should start to have some muscle tension, restlessness, frequent sneezing and seem to cry a lot. If that happens, there is a Special Care Nursery (SCN) where I will go to get better.

I know it is hard to hear that I might not go home with you but the SCN staff are experts in caring for babies just like me. The Director of the SCN is Dr. Karen Harvey-Wilkes. She will begin treatment that will help my symptoms and begin my recovery. I will have physical therapy to help my muscles relax. I want you to come in to feed and take care of me any time. You can also call for updates on my progress day or night. And Mom, even if I don't feel so good for a little while, the treatment will eventually make me well enough to come home to you. I may need a pacifier; can you get one for me? I wonder, will we be breastfeeding? I hope so!

It is hard to predict how long my treatment will last. The doctors and nurses are here to explain everything each step of the way. Don't be afraid to ask them questions. You will also meet Laura and Penny. They are the social workers who will talk to the Department of Children and Families (DCF) and file the required 51A. Laura and Penny will help connect us with support services for after I go home.

I am so happy you are my mother. Mom, I am willing to do this day by day until my symptoms are better. What a team!

 **Hallmark Health**
www.hallmarkhealth.org

Neonatal (Newborn) Abstinence Syndrome – NAS

What is it?

- Neonatal abstinence syndrome (NAS) is a term for a group of problems a baby experiences when withdrawing from exposure to drugs taken during pregnancy.
- Drugs such as methadone, heroin, cocaine, klonopin, and other prescription drugs pass through the placenta to the baby during pregnancy.
- Babies also withdraw from cigarette and alcohol use.
- The baby becomes addicted during pregnancy and begins to withdraw from the drugs after birth.
- Symptoms can begin 1-7 days after birth, or may take 5-10 days to appear.
- The NAS scoring system assigns points based on how severe the symptoms are.
- Among the symptoms that receive scores are excessive or high pitched cry, tremors, increased muscle tone, diarrhea, poor feeding, not sleeping between feedings, increased temperature, and increased respirations.
- When baby is born, urine and stool samples are sent to the lab.
- There will be a report to The Department of Children and Families who will call you to discuss your health and the baby's safety. (Please see the attached "What to expect from a mandated report to the Massachusetts Department of Children and Families.")
- If the baby shows symptoms of withdrawal, your baby will come to the Special Care Nursery to be observed, monitored, and followed by our special team of caregivers.
- The team includes a neonatologist, nurses, social workers, physical therapists, dietitian, and cuddlers. Cuddlers are volunteers who hold fussy babies with your permission.
- Some babies need medicine to treat withdrawal symptoms.
- The medicines commonly used are neonatal morphine solution and/or phenobarbital.
- The dose will depend on the symptoms, and how your baby responds to the medicine.
- Each baby will be continually evaluated.
- The length of stay depends on our baby's symptoms and his or her response to treatment.
- A stay can be anywhere from 1-8 weeks.
- Your discharge plan will include a visit from the visiting nurse, pediatrician follow-up care, and possibly Early Intervention.



**What to expect from a mandated report to the Massachusetts
Department of Children and Families**

Anytime a baby has been exposed to an addictive (and/or illicit) substance, prescribed or otherwise, the baby runs the risk of withdrawal or exposure to unsafe conditions. Therefore, DCF mandates that health care professionals working with substance exposed newborns file a report to their agency; it is called a 51-A.

The report will include:

- Demographic information on the mother, the father and/or any other adult caring for the baby including where the baby and caregivers will reside after discharge.
- List of substances identified in report.
- List of mental health professionals, substance abuse recovery professionals, legal or DCF services professionals working with the newborn's adult caregivers.
- The family's strengths and supports system.

The report will lead to an "initial assessment."

- A DCF worker will call you to schedule a time to visit you and all caregivers, see the place the baby will reside, and meet the baby.
- The worker will speak with your health care providers, current DCF providers and current parole professionals.
- He/she will work with you to ensure that you have plenty of support in parenting, substance abuse recovery, mental and physical health, financial stability, housing and childcare.
- With you, the worker will either decide to open the case (DCF would remain involved in an ongoing assessment and support for 30-45 days) or close the assessment after 10 days.
- *DCF's goal is usually the same as the family's; to make sure the baby and the family members are safe and healthy.* Most caregivers ultimately find the process supportive and helpful.

The hospital social workers collaborate and exchange information with DCF, but do not participate in investigating the health and safety of the family caring for the baby. They provide support, education, counseling and referrals to the families of newborns. Please feel free to call Laura or Penny with any questions or concerns at (781)979-3642.



**Hallmark Health
Melrose Wakefield Hospital**

Date TIME	score					
Excessive Cry	2					
Continuous Cry	3					
Sleeps <1 hour	3					
Sleeps <2 hours	2					
Sleeps <3 hours	1					
Hyperactive Moro Reflex	2					
Markedly Hyperactive Moro	3					
Mild Tremors Disturbed	1					
Moderate-Severe Tremors Disturbed	2					
Mild Tremors Undisturbed	3					
Moderate Tremors Undisturbed	4					
Increased Muscle Tone	1-2					
Frequent Yawning >3-4X/int	1					
Excoriation (area:)	1					
Myoclonic Jerks	3					
Generalized Convulsions	5					
Sweating	1					
Fever <101(99-100.8F/ 37.2-38.2C)	1					
Fever >101 (38.4 C or higher)	2					
Mottling	1					
Nasal Stuffiness	1					
Sneezing >3-4X/int	1					
Nasal Flaring	2					
Respiratory Rate >60/ min	1					
Respiratory Rate >60/ min w/ retractions	2					
Frantic Sucking	1					
Poor Feeding	2					
Regurgitation	2					
Projectile Vomiting	3					
Loose Stool	2					
Watery Stool	3					
Totals						
Initials						
<i>Signatures</i>	<i>Initials</i>	<i>Signatures</i>	<i>Initials</i>			

Finnegan Scoring Definitions

Central Nervous System Disturbances:

Crying: Excessive	Infant is unable to decrease crying in 15 seconds using self-consoling measures and then cries continuously for up to 5 minutes despite caregiver intervention.
Crying: Continuous	Infant is unable to decrease crying in 15 seconds by self-consoling measures and then cries continuously for greater than 5 minutes despite care giver interventions.
Sleep	Score is based on the longest period of sleep displayed by infant during scoring interval, including deep and light sleep, and sleep while being held. If infant is feeding every 3 hours, score 1 if sleep <2 hours, score 2 if sleeps <1 hour, and 3 if infant does not sleep between feeds.
Hyperactive Moro Reflex	Lift baby slightly off the bed by the wrists or arms and allow the baby to fall back on the bed. (D not perform when the baby is crying or irritable). Score if baby exhibits pronounced jitteriness or the hands at the end of the Moro reflex.
Markedly hyperactive	Baby exhibits jitteriness and repetitive jerks (clonus) of the hands and arms at the end the Moro reflex.
Moro Reflex	Observable tremors of hands or feet while being handled.
Mild Tremors:	
Disturbed	
Moderate-Severe Tremors:	
Disturbed	Observable tremors of arms or legs while being handled.
Mild Tremors:	
Undisturbed	
Moderate-Severe Tremors:	
Undisturbed	Observable tremors of arms or legs when infant is asleep, drowsy, or awake and not being handled by caregiver.
Increased Muscle Tone	Assess when infant is quiet and awake. Do not assess while infant is asleep or crying. Score 2 if infant exhibits tight flexion of arms and legs (unable to extend) or total body rigidity without heel lag when pulled to a sitting position. Score 1 if tone increased but not "rigid".
Frequent Yawning	Yawning greater than three times during scoring interval.
Excitation	The result of constant rubbing or extremity against flat surface. Score if present on chin, knees, cheeks, elbows, toes or nose. Score when area first presents; score again if increases or appears another area.
Myoclonic Jerks	Score if infant expresses short, quick contractions of muscles of face or extremities or if jer movements of arms or legs are observed.
Generalized Convulsions	Score if generalized seizure actively is present (jerking movements that cannot be stopped by touching or flexing the extremity).

Metabolic and Respiratory Disturbances:

Sweating	Score if wetness is felt on infant's forehead, upper lip or back of neck. Do not score if sweating is result of overheating due to swaddling.
Fever	Axillary temp 99.0-101.0 °F (37.2-38.3 °C) – Score as 1; Axillary temp > 101.0 (38.3) – score as 2.
Mottling	Score if mottling is present on infant's chest, trunk, arms or legs.
Nasal Stuffiness	Score if infant exhibits noisy respirations due to presence of nasal exudate.
Sneezing	Score if infant sneezes more than three times within a scoring interval.
Nasal Flaring	Score if not due to lung or airway disease.
Respiratory Rate	Assess when infant is sleeping or quietly awake. RR>60 – score as 1; RR>60 with retractions – score as 2.

Gastrointestinal Disturbances:

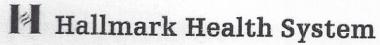
Frantic Sucking	Score if infant exhibits increased rooting while displaying rapid sucking movements with hand across mouth in an attempt to suck on fist, hands, or pacifier.
Poor Feeding	Score if infant exhibits excessive sucking prior to being fed yet sucks infrequently during feed taking only small amounts of formula/EBM and/or demonstrates uncoordinated suck/swallow reflex.
Regurgitation	Score if regurgitation occurs 2 or more times during a feeding and is not associated with burping or wet burps.
Projectile Vomiting	Score if one or more projectile vomiting episodes occur either during or immediately after feeding. Projectile vomiting is explosive and extremely forceful.
Loose Stool	Liquid stool that does not leave a water ring in the diaper; may or may not be explosive.
Watery Stool	Soft, mushy, or hard stool accompanied by a water ring on the diaper.

References: D'Apolito, K.A.

A scoring system for assessing neonatal abstinence syndrome. University of Washington Medical Center, Seattle, WA, 1994.

Greene, CM and Goodman, MH

Neonatal abstinence syndrome: strategies for care of the drug-exposed infant. Neonatal Network: Jul-Aug; 22:15-25, 2003.



585 Lebanon Street
Melrose, Massachusetts 02176
(781) 979-3000

Special Care Nursery Helpful Hints for Parents and Caregivers

Welcome to the Special Care Nursery (SCN). We are located on the 4th floor of the Melrose-Wakefield Hospital and our phone number is (781)979-6400. You may come anytime.

- Visiting the secure nursery or obtaining information by phone requires an ID wristband with identifying number.
- Family and friends may visit with the banded caregiver provided that they are healthy.
- Siblings are also welcome except during flu season (October 15th to April 15th).

We are staffed by neonatologists, nurses, lactation specialists, social workers and physical therapists who will partner with you in the care of your child.

- One of the most important factors in your baby's development is human touch, especially yours. Infants love to be held close to your skin.
- We encourage you to be with the baby as much as possible. (However, if you are not able to visit, we have a volunteer "Cuddle Program," staff can provide more information).
- The nursery is purposefully dark and quiet to reduce stimulation. The babies need lots of rest. Please speak quietly, keep cell phones on silent and try not to wake your sleeping baby. (Feel free to use text mode while the baby is safely in the crib or swing). For quiet, safety and confidentiality, we ask that you stay in your baby's bassinet area when visiting and holding your child.
- Breastfeeding is encouraged and supported except in cases of certain illnesses or substance use.

As the time nears for your baby to go home, the medical staff will discuss discharge plans, aftercare referrals and provide teaching about the care at home. Please feel free to call after discharge with any questions or concerns.



BREASTFEEDING & METHADONE? YES, YOU CAN!

Many babies have breastfed successfully while their moms were taking Methadone as prescribed by a physician.

Methodone does transfer into mom's milk, but in fairly small amounts. The amount the baby receives is not enough to keep the baby from experiencing withdrawal symptoms, and has not been shown to have any long term harmful effects.

There are 3 very important things to remember if you are breastfeeding a baby while taking methadone:

1. You **MUST** take your methadone as prescribed and not any more. There have been reports of harmful effects to infants when mothers were taking unprescribed methadone.
2. You can **NEVER** mix methadone with any other street drugs, particularly narcotics. Taking both together and then breastfeeding can have serious effects on your baby. You may need to take some type of pain medication for recovery after a cesarean, but this should only be for a short time.
3. When you decide to stop breastfeeding, and if you are still taking methadone, you will need to stop gradually. That means that if you are breastfeeding 8 times each day you should not suddenly stop breastfeeding all together. Doing this may cause the baby to go through a period of withdrawal. Instead, you will slowly decrease the number of breastfeedings each day until you are able to stop completely.

Even though it is safe to breastfeed while taking Methadone, the nurses will monitor your baby for any unusual symptoms such as more than usual sleepiness or fussiness, and you can watch for this too.

You may find that if your baby needs to stay in the hospital more than a few days, breastfeeding gives you that special connection that only you can have with your baby. Skin-to-skin contact (baby in diaper only, next your skin, covered with a blanket) while breastfeeding is also encouraged and is often calming to the baby. If you are separated from your baby, you can pump your milk and bring it in, so you can still provide that special gift, even when you are apart.

We are happy that you have made the decision to breastfeed your baby and are here to support you. Call the Breastfeeding Support Center if you have any further questions or concerns.

781-979-MILK (6455)

C:\Documents and Settings\folem\My Documents\BREASTFEEDING & METHADONE.doc



BREASTFEEDING & SUBUTEX? YES, YOU CAN!

Many babies have breastfed while their moms were taking Subutex, and no harmful effects have been reported.

Subutex does not transfer well into mother's breast milk, so the milk that the baby gets has very little of the medication in it. Also, once that small amount gets into the baby's stomach, it does not transfer well to the baby's blood so it has very little effect on the baby. This is why it is considered acceptable to breastfeed while taking Subutex.

Even though it is safe to breastfeed while taking Subutex, the nurses will monitor your baby for any unusual symptoms such as more than usual sleepiness or fussiness, and you can watch for this too.

You may find that if your baby needs to stay in the hospital more than a few days, breastfeeding gives you that special connection that only you can have with your baby. Skin-to-skin contact (baby in diaper only, next your skin, covered with a blanket) while breastfeeding is also encouraged and is often calming to the baby. If you are separated from your baby, you can pump your milk and bring it in, so you can still provide that special gift, even when you are apart.

We are happy that you have made the decision to breastfeed your baby and are here to support you. Call the Breastfeeding Support Center if you have any further questions or concerns.

781-979-MILK (6455)



Moral Distress in NICU Nurses Who Care for Infants with Neonatal Abstinence Syndrome



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Denise Maguire, PhD, RN, CNL

Study Funding

- Established Researcher's Grant, Department of Sponsored Research, University of South Florida, Tampa, FL
- Pilot Study Grant, College of Nursing, University of South Florida, Tampa, FL

Acknowledgments

All-Children's Hospital, St. Petersburg,
Florida: Study Site

Ms. Selena Thomason- Transcriptionist
Extraordinaire

The nurses who gave of their time to share
their “stories” with me.



IRB Approval

- Permission to conduct study was granted by All Children's Hospital IRB and the University of South Florida IRB.

Background of Study

- Hearing the “lived experiences” of masters and doctoral students over the last 10 years.
- NICU nurses repeatedly related extremely compelling experiences
- Consulted with Professor Carol Taylor, PhD, RN, Kennedy Institute of Ethics, Georgetown University
 - **“Ask Them to Tell You Their Stories!”**

Legal and Ethical Obligations

- Nurses must adhere to both legal and ethical obligations while performing the responsibilities associated with their profession.
- Nurse practice acts typically prescribe the legal boundaries or scope of practice in which the nurse may practice nursing.
- Ethical expectations are delineated in the American Nurses Association Code of Ethics (ANA) (2001), which in itself, can be interpreted as a legal obligation.
- Code of Ethics follows Kant's deontological theory. Emphasizes our “duty” to promote goodness and avoid harm.

Moral Agency

- Morality is what we believe is right/wrong; good/bad; virtuous /evil.
- Taylor (2008) defined moral agency as the capacity to consistently act in an ethical manner. Moral agency entails a certain set of competencies in matters ethical as well as moral character and motivation. Each individual, as a moral agent, exists within complex relations, which are often complicated by differences, particularly differences in power (Taylor).

Moral Integrity

The moral agency of an individual, group of individuals, or an institution may be constrained by differences in relations. If this occurs to a nurse or group of nurses they may feel they are not fulfilling their ethical obligations and have compromised their moral integrity by being unable to adhere to moral principles such as beneficence, nonmaleficence, autonomy, or justice (Taylor).

Moral Distress

- Moral distress has been defined by Corley, Elswick, Gorman, & Clor (2001) as being “the painful psychological disequilibrium that results from recognizing the appropriate action, yet not taking it because of such obstacles as lack of time, supervisory reluctance, an inhibiting medical power structure, institution policy, or legal considerations” (p. 250-251).

Purpose of Study

- The primary aim of this qualitative methods study was to describe the lived experiences of NICU nurses with ethical and morally challenging issues. One on one interviews revealed that two ethical issues were predominant in all nurses interviewed: (1) Quality of life for the neonate and (2) Caring for infants experiencing withdrawal from opioids (neonatal abstinence syndrome).
- The participants perceptions of the lived experience of caring for infants with neonatal abstinence syndrome will now be presented.
-

Neonatal Abstinence Syndrome

- Neonatal abstinence syndrome (NAS) is a generalized syndrome characterized by central nervous system hyperirritability, respiratory distress, and gastrointestinal dysfunction, (Cleary et al., 2010: Bakstad, Sarfi, Welle-Strand & Ravndl, 2009). This syndrome is associated with exposure in utero to opiates (morphine, codeine, and opium), semi-synthetic opiates (heroin, oxycodone), and synthetic narcotics (methadone, vicodin, buprenorphrine, fentanyl, and meperidine. According to a Cochrane review (Osborne, Jeffery, & Colree, 2005) 48-94% of newborns exposed to an opioid in utero will develop this syndrome. In recent years there has been an increase in infants with NAS who have been exposed to a multiple drug regimen (poly-drug exposure).

Treatment

Initial symptomatic care includes swaddling, holding, skin to skin contact, decreased stimulation (light, noise, and tactile), and pacifiers. Infants should be fed on demand. It is essential that the infants are not over stimulated during feedings; infants should not be wakened between feedings.

Pharmacologic intervention is indicated for evidence of acute withdrawal such as seizures and/or elevated scores on an objective measure (e.g. Finnegan Scale).

Morphine is currently drug of choice; phenobarbital is used later in treatment.

Pill Mills: The Dark Side of the Sunshine State

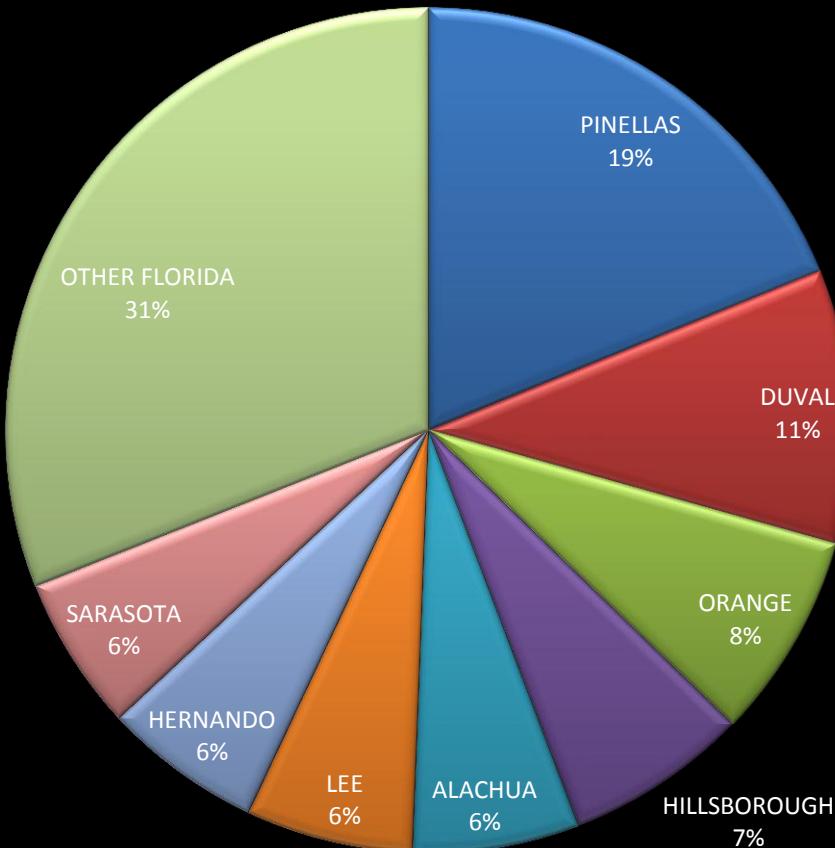
- Approximately 7 people die per day in Florida from overdose/abuse of prescription drugs.
- We have more pain clinics than we do Burger Kings.
- Oxycodone is the most frequently abused drug.

A Florida Pill Mill



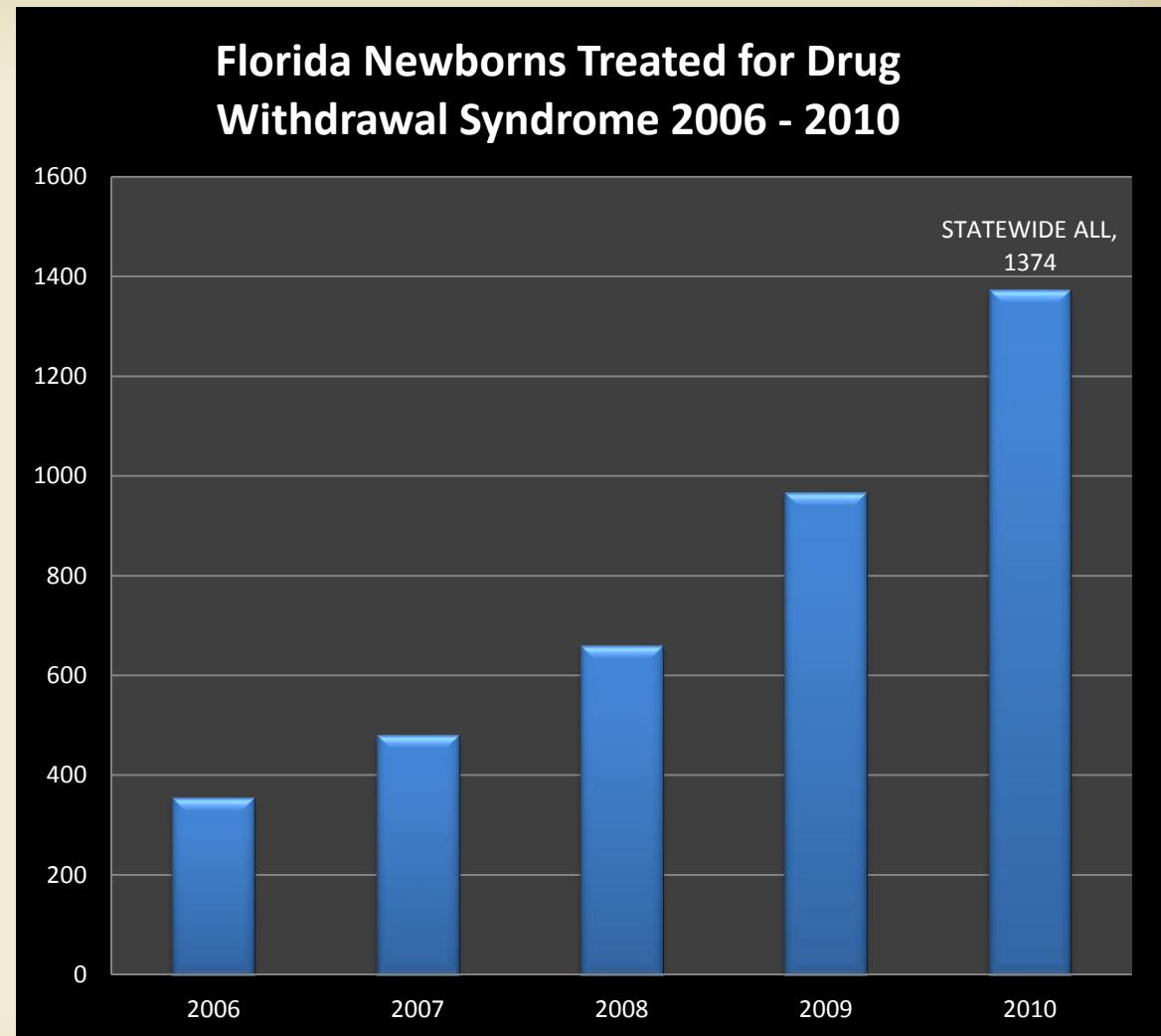


Newborns Treated for Drug Withdrawal Syndrome Highest 8 of the 38 Florida Counties 2010



SOURCE: Florida Agency for Health Care Administration

Statewide, the number of babies treated for drug withdrawal syndrome skyrocketed yet again, **climbing 42 percent between 2009 and 2010.**



SOURCE: Florida Agency for Health Care Administration

Newborns Treated for Drug Withdrawal Syndrome Hillsborough and Pinellas by Hospital

County	Facility Name	2006	2007	2008	2009	2010
HILLSBOROUGH	COUNTY TOTAL	36	22	34	44	92
HILLSBOROUGH	BRANDON REGIONAL HOSPITAL	2	6	1	6	9
HILLSBOROUGH	SOUTH FLORIDA BAPTIST HOSPITAL	0	0	1	0	0
HILLSBOROUGH	ST JOSEPHS HOSPITAL	4	4	10	17	36
HILLSBOROUGH	TAMPA GENERAL HOSPITAL	29	11	17	17	41
HILLSBOROUGH	UNIVERSITY COMMUNITY HOSPITAL	1	1	5	4	6
PINELLAS	COUNTY TOTAL	42	57	94	155	248
PINELLAS	ALL CHILDREN'S HOSPITAL INC	9	9	26	54	114
PINELLAS	BAYFRONT MEDICAL CENTER INC	14	20	34	42	26
PINELLAS	HELEN ELLIS MEMORIAL HOSPITAL	1	2	3	2	11
PINELLAS	MEASE COUNTRYSIDE HOSPITAL	8	13	17	30	56
PINELLAS	MORTON PLANT HOSPITAL	9	8	12	19	37
PINELLAS	ST PETERSBURG GENERAL HOSPITAL	1	5	2	8	4

SOURCE: Florida Agency for Health Care Administration



County	2006	2007	2008	2009	2010
PINELLAS	42	57	94	155	248
DUVAL	41	62	53	108	138
ORANGE	36	34	71	69	104
HILLSBOROUGH	36	22	34	44	92
ALACHUA	11	18	33	63	84
LEE	15	12	26	66	84
HERNANDO	12	25	38	58	80
SARASOTA	8	11	11	33	78
BREVARD	8	25	41	41	58
BROWARD	11	33	33	36	58
ESCAMBIA	36	46	46	56	45
VOLUSIA	4	10	16	28	44
PALM BEACH	18	18	34	38	34
MIAMI-DADE	13	18	25	22	30
COLLIER	14	17	26	23	24
CHARLOTTE	3	2	5	13	21
CLAY	8	17	5	13	20
PASCO	4	4	6	13	18
MANATEE	7	3	12	14	14
LEON	0	7	10	5	12
OKALOOSA	4	3	4	8	12
MARION	6	8	5	6	10
POLK	9	9	5	6	10
BAY	1	2	6	9	9
COLUMBIA	0	0	2	5	6
ST. LUCIE	3	3	1	6	6
LAKE	2	3	1	2	5
MARTIN	0	4	4	2	5
PUTNAM	0	0	1	0	4
ST. JOHNS	0	2	1	6	4
CITRUS	0	0	0	0	3
DESOTO	0	0	0	0	3
INDIAN RIVER	0	0	1	7	3
NASSAU	1	0	1	2	2
OSCEOLA	0	3	4	6	2
WALTON	0	1	1	1	2
HIGHLANDS	0	2	1	0	1
SEMINOLE	1	0	2	2	1
STATEWIDE	354	481	659	966	1374

Newborns Treated for Drug Syndrome

Florida Counties Sorted Highest to Lowest

SOURCE: Florida Agency for Health Care Administration

Methods

- Design: Qualitative methods study using one-on one interviews.
- Purposive snowball sampling used.

Study Setting

- The study was conducted in the neonatal intensive care unit located in a 259 bed specialty licensed children's hospital in Pinellas County on Florida's west coast. Within the hospital there is a 97-bed Neonatal Intensive Care Unit (NICU) (an entire floor of the hospital).
- About 73 % of inpatients come from five counties to the north, south and east of the hospital region (Pasco, Pinellas, Hillsborough, Manatee & Sarasota Counties); nearly a third come from 12 additional counties in west central/southwest Florida. The remaining 7% come from the southeast coast of Florida, other states and other countries.

Participants

- Flyers placed in lounges and on email.
- Private one-on one interviews arranged to fit participant's schedule.
- 16 nurses participated in the study
- 14/16 interviews done at ACH; 2/16 at USF.
- Interviews were digitally recorded; confederate names assigned to each participant.
- Participants received a \$25.00 gift certificate to local restaurants.

Admission Unit All Children's



Caring for Infants

- All nurses expressed frustration in caring for infants with NAS, reporting there was little they could do to comfort the infants. The infants demand all of their attention during their shift, but the nurses said "nothing comforts the infant".
- ***"They are here quite a while. The withdrawal process isn't fast. So, they are here for a long time and are just so sad. Because they just scream and scream and scream. Nothing comforts... You know, sometimes nothing comforts them."***
- ***"You cannot have a term baby in a hospital for 2 months...3 months, 4 months. It's just not right. It's just...how could that be good for anybody? "***
-

Caring for Infants

- “*You can't do anything sometimes for them, you know? You change their diapers, you hold them, you feed them, you give their morphine, you do everything, and they are just hysterical. So that is frustrating. Especially when you have a busy assignment and you have one kid that is screaming bloody murder the whole night and you can't do anything. You feel bad as a nurse.*”
- “*This is definite withdrawal. They sweat like menopause night sweats. You go in and that baby will be soaking wet. Just sweating up a storm. Frantically, like you put the bottle near the mouth, and they're like making desperate sounds but he won't suck. You can't calm him enough to suck off it. It's just... desperate sounds.*”

Infant Experiencing Withdrawal



Interacting with Parents

- Nurses in this study reported that mothers typically visited sporadically, continued their drug habit, and attempted to manipulate the system. Most were not involved in the daily care of their infants, and could not recognize signs of distress or withdrawal. Often they visited at night or in the early hours of morning.
- Nurses reported parents falling asleep while holding their baby, ‘texting on the phone,’ stealing diapers and formula.
- Parents could be staying at the Ronald McDonald House and still not visit.

Interacting with Parents

“ ‘Fix my baby! What have you done? He ate fine for me last night. He always eats for me.’ ” And I always put it right back on them, that's just me but I turn it around on them. “That is wonderful, and he eats again at 1 o'clock, you need to be here, because if I'm not feeding him right and you have the magic touch, you need to feed him. That's your role, that's your baby. Show the world that you can do it.” “Oh, I have to go to the methadone clinic at 3.”

Interacting with Parents

- “I just get tired of dealing with stupid people...people that don’t care for themselves, much less for their kids. And then they know how to work the system, they know how to come up here and make a big scene. Then they are the best parent in the world all of a sudden. And demanding. And that’s frustrating when you didn’t care about your kid for 9 months when you were doing cocaine and whatever. But now that your baby is born, you’re going to throw a fit about every tiny, little thing. That gets frustrating sometimes. And a lot of time they come in here messed up. So, trying to deal with people that are high...if we notice it, we’ll try and kick them out...But there are so many of them. It’s crazy.”

Discharging Babies Home!

- As hard as it was to take care of the infants in the hospital, many voiced concerns about sending the infants home.
- **“The worst part...was that I had to be the one to discharge him. And I was just afraid he was going to be screaming in the middle of the night and she was just going to drop him, throw him at a wall.”** This nurse coached the mother about what to do if her son could not stop crying. **“You need to promise me right now that when (your baby) does that, you will put him in his crib, put the side rail up, and walk out of the room.”**

Discharging Babies Home

- Many nurses shared the concern that some infants were allowed to go home with their parent, when, in their minds, the parents were not responsible enough
- ***If you can't take care of yourself without using drugs on a daily basis, how in the world are you going to take care of a child who is more difficult than most children? As a society, how are we sending these children home with these moms and dads?"***

Data Analysis

- Sampling is typically terminated in qualitative studies when no new information is forth coming (data saturation); redundancy is the primary criterion..
- Each recorded interview was transcribed verbatim and the digital recording was erased. The transcriptions were stored on a password protected computer in a locked office. An electronic copy of interview was then sent to each of the participants for member-checking.
- Transcribed interviews were analyzed, utilizing the Atlas.ti software, to identify themes that were common to all the participants

Thematic Analysis Results

- Caring for Infants with NAS
- Interacting with parents of infants
- Concerns about discharging infants

Interpretation of Findings

- Nurses experienced many challenges to their moral integrity.
- Principles (beneficence, nonmaleficence, justice) are being challenged and not upheld.
- Nurses found the experience to be morally offensive and at times, repugnant.
- Difficult for the NICU nurse to cope with the “addictive personality.”
- Frustration with lack of control over the situation.
- Overriding concern was outcome of infant.

What Do We Do Next?

- Consulting with All-Children's and Mease Morton Plant Hospitals
- Appointed to Healthy Start Task Force Pinellas County
- Member of USF Health Women's Initiative

Implications for Research

- Conduct interviews with mothers-In Progress
- Stress Management Classes for Nurses
 - Interacting with the addictive personality
 - Pharmacological manage of substance abusers
- Parental classes for mothers
- Evaluate length of stay, parental satisfaction, nurses level of moral distress, biological parameters.

A Beacon of Hope In The Night



Open Letter to the Media and Policy Makers Regarding Alarmist and Inaccurate Reporting on Prescription Opioid Use by Pregnant Women

March 11, 2013

To whom it may concern:

A substantial increase has been noted in the number of pregnant women and newborns who test positive for illegal as well as legal opioids, including those utilized as prescribed as well as those misused and/or diverted. A great deal of experience has been gained over the course of almost 50 years regarding the effects of prenatal opioid exposure on expectant mothers and their babies, and guidelines have been established for optimal care of both. And yet, reporting in the popular media continues to be overwhelmingly inaccurate, alarmist and decidedly harmful to the health and well-being of pregnant women, their children, and their communities.

As medical and psychological researchers and as treatment providers with many years of experience studying and treating prenatal exposure to psychoactive substances, as well as treatment providers and researchers with many years of experience studying addictions and addiction treatment, we are writing to urge that policies addressing prenatal exposure to opioids, and media coverage of this issue, be evidence-based rather than perpetuate and generate misinformation and prejudice.

No newborn is born “addicted”

Popular media repeatedly and inaccurately describe children exposed to various drugs *in utero* as “addicted,” a term that is incorrect and highly stigmatizing. Addiction is a technical term that refers to compulsive behavior that continues in spite of adverse consequences. In fact, babies cannot be born “addicted” to anything regardless of drug test results or indicia of physical dependence. Evidence of physiologic dependence on (not addiction to) opiates has been given the name neonatal abstinence syndrome (NAS), a condition that is diagnosable and treatable. And yet, as the following examples demonstrate, news reports typically and inaccurately describe newborns as addicted (emphasis added).

- “In Broward County, there has been an alarming jump in the number of babies born to pill-using mothers; *babies who are themselves born addicted.*” (KTHV Television, [More Pill-Using-Mothers Delivering Addicted Babies](#), July 29, 2011)
- “There’s a growing epidemic of *babies being born addicted to prescription drugs* ingested by young mothers...” (Bradenton Herald, [Prescription-Abuse Babies a Growing ‘Crisis’ in Manatee, Say Advocates](#), Nov. 9, 2011)
- “The number of *babies born addicted* to the class of drugs that includes prescription painkillers has nearly tripled in the past decade...” (USA Today, [Addicted Infants Triple in a Decade](#), May 1, 2012)

- “In the past decade, the number of *babies born addicted to opiates* has tripled.” (The Huffington Post, [More Babies Born Addicted to Painkillers, Multiple Reports Show Growing Epidemic](#), July 13, 2012)
- “Once, every hour in the U.S. a *baby is born addicted to the painkillers* that swallowed up its mother.” (WKYC Television, [Tiniest Victims of Ohio’s Painkiller Epidemic](#), Aug. 1, 2012)
- “10 percent of the *babies born are addicted to opiates*.” (WSAZ News Channel, [Scioto County and Portsmouth Make Strides in the War on Drugs](#), Oct. 31, 2012)
- “A new study showing a major increase in Tennessee *babies born addicted to drugs* has prompted the state Health Department to require hospitals to report that information.” (WFPL News, [Tennessee Requiring Hospitals to Report Babies Born Addicted to Drugs](#), Dec. 5, 2012)

In addition to labeling newborns addicted when they are not, major news outlets have also drawn parallels between children born to women who have used opioids during their pregnancy and those who, a decade ago, were branded “crack babies.” For example, Brian Williams began an NBC news report by saying, “For those of us who were reporters back in the 1980s, it was an awful new trend we were covering at the time, and it was the first time our viewers were hearing about the young, innocent infants. A generation of crack babies, born addicted to drugs because of their mothers’ habit. Sadly, a new generation has meant a new habit – prescription pain meds, Oxycontin, Vicodin; other powerful drugs in that same category. And now we are seeing the infants born to mothers abusing these drugs.” (NBC News, [Prescription Drug Addiction Among Pregnant Women Becoming ‘Monstrous Tidal Wave’](#), July 5, 2012) An ABC news report likewise claimed: “The increasing numbers of women who abuse prescription painkillers while pregnant are delivering the crack babies of the 21st century, specialists say.” (ABC News Medical Unit, [Newborns Hooked on Mom’s Painkillers Go Through Agonizing Withdrawal](#), Nov. 14, 2011) And The Wall Street Journal described newborns exposed prenatally to cocaine and methadone treatment as “reminiscent of the ‘crack babies’ of the 1980s and 1990s.” (Wall Street Journal, [Pain Pills’ Littlest Victims](#), Dec. 28, 2012)

In more than 20 years of research, none of the leading experts in the field have identified a recognizable condition, syndrome, or disorder that should be termed “crack baby” (See [Open Letter To the Media](#), February 25, 2004). Rather than learning from its alarmist and false reporting about pregnant women and cocaine use (e.g., New York Times, [The Epidemic That Wasn’t](#), Jan. 26, 2009), media outlets have now irresponsibly revived the term “crack baby” and created new, equally unfounded and pejorative labels such as “oxy babies” or “oxy tots.” (FoxNews, ['Oxytots' Victims of Prescription Drug Abuse](#), October 28, 2011; The Examiner, ["Oxytots": A National Disgrace](#), Oct. 30, 2011)

Equally unjustified is the suggestion that some women who become pregnant and carry their pregnancies to term give birth not to babies but rather to “victims.” As noted above, a story in The Wall Street Journal was headlined *Pain Pills’ Littlest Victims*. (Wall Street Journal, Dec. 28, 2012) Another recent article in USA Today referred to newborns prenatally exposed to prescription opiates as “the tiniest victims.” (USA Today, [Kentucky Sees Surge in Addicted Infants](#), Aug. 27, 2012) Of course, where there are victims, there also are perpetrators – in this case, pregnant women and mothers. None of these women – whether receiving methadone or

other opioids for the management of pain, obtaining federally-recommended treatment of dependence, or misusing opioids and experiencing a dependency problem – may fairly be characterized as perpetrators or victimizers.

The most respected and objective authorities in the U.S. and throughout the world, including the World Health Organization, have determined that drug addiction is not a “bad habit” or willful indulgence in hedonism, but a chronic medical condition that is treatable but – as yet – not curable. Demonizing pregnant women creates an environment where punishment rather than support is the predominant response, and will inevitably serve to discourage women from seeking care.

Long-term implications for offspring misrepresented

News media also typically report or suggest that “those born dependent on prescription opiates ... are entering a world in which little is known about the long-term effects on their development.” (New York Times, [Newly Born, and Withdrawing from Painkillers](#), April 9, 2011) And yet, when controlling for factors such as economic status, access to healthcare, and concomitant medical problems, including use of nicotine products and alcohol, decades of studies reported in the professional literature have failed to demonstrate *any* long-term adverse sequelae associated with prenatal exposure to opioids, legal or illegal. On the other hand, it is not an exaggeration to state that labels such as “victim” or “tiny addict” or “born addicted” carry with them severe negative consequences, both medical and social. Children so labeled are at substantial risk of stigma and discrimination in educational contexts starting at the pre-school level. They may be subject to medical misdiagnosis and unnecessary, detrimental separation from loving and supportive families as a result of ill-informed and inappropriate child welfare interventions.

It should be clear from the above that we are not preoccupied with semantic niceties, but deeply concerned about reporting that, very literally, threatens the lives, health, and safety of children.

Neonatal abstinence syndrome, when it occurs, is treatable and has not been associated with long-term adverse consequences

Both the occurrence and severity of NAS have been shown to be affected by a variety of factors that are unrelated to possible pharmacological effects of prenatal exposure to opioids. For example, a 2006 study demonstrated that babies who stayed in their mothers’ room while in hospital (i.e., “rooming in”) rather than being placed in neonatal intensive care units (NICU) had less need for treatment of NAS, shorter length of hospital stay, and significantly greater likelihood of being discharged home in the custody of their mothers. Similarly, a 2010 study found that only 11% of babies who boarded with their mothers required treatment of NAS compared to more than four times as many who were placed in an NICU.

Moreover, it has long been known that NAS, when it occurs, can be treated effectively. NAS can be evaluated and managed with scoring systems and treatment protocols that have been available for decades in standard textbooks and in numerous articles in the professional literature. Appropriate care, which may include breastfeeding and "comfort care" (e.g.,

swaddling and skin-to-skin contact between mother and baby), is often sufficient to prevent or minimize signs of distress in the baby. There simply is no reason why babies should as stories report “go through agonizing withdrawal” or demonstrate “...merciless screams, jitters and unusually stiff limbs.” News reports describing newborns suffering suggest lack of appropriate medical training and the failure to provide optimal medical care rather than inevitable, untreatable, effects of prenatal exposure to opioids. (e.g., The Gadsen Times, [Our View: Addicted at Birth](#), Nov. 15, 2011; PBS Newshour, [Painkiller ‘Epidemic’ Deepens in U.S.](#), Nov. 2, 2011; Knoxville News Sentinel, [Drug-addicted Babies Difficult to Treat](#), Nov. 1, 2011)

Media misinformation and stigmatizing characterizations discourage appropriate, federally recommended treatment

Recent reporting also frequently dangerously mischaracterizes methadone maintenance treatment as harmful and unethical. For example, a CNN story irresponsibly portrays a woman’s decision to follow recommended treatment as a form of abuse:

Narrator 1: Guided by her doctor, April did what she thought was best for her baby and stayed on methadone for her entire pregnancy. The end result? Mariah was born dependent on drugs.

Narrator 2: What did that feel like to know that your use of methadone had caused her so much suffering?

April Russell: Oh it’s, I mean, I can’t explain it. I mean, it killed me. I mean, still today I mean it’s, it’s hard (April starts to cry). But, (stops talking due to crying), sorry.

(CNN video broadcast, [One Baby Per Hour Born Already in Withdrawal](#), April 12, 2012) Similarly, NBC News reported that a pregnant woman in treatment “can’t save her baby from going through withdrawal. Because methadone is another form of medication similar to painkillers, there is a good chance her baby will be born addicted to that drug.” (NBC News, July 5, 2012) And The New York Times reported that “those who do treat pregnant addicts face a jarring ethical quandary: they must weigh whether the harm inflicted by exposing a fetus to powerful drugs, albeit under medical supervision, is justifiable.” (New York Times, April 9, 2011)

The evidence for the efficacy of methadone maintenance treatment – most particularly its use in the care of pregnant women – has been overwhelmingly consistent for almost half a century. The highest U.S. government authority on drug abuse treatment, the Substance Abuse and Mental Health Services Administration, summed it up in a pamphlet it produced several years ago and continues to distribute. It is directed to pregnant, opioid-dependent women and states in unusually clear and concise terms: “If you’re pregnant and using drugs such as heroin or abusing opioid prescription pain killers, it’s important that you get help for yourself and your unborn baby. Methadone maintenance treatment can help you stop using those drugs. It is safe for the baby, keeps you free of withdrawal, and gives you a chance to take care of yourself ... Methadone maintenance treatment can save your baby’s life.” Recently, buprenorphine treatment has also been used effectively to treat opiate addiction in pregnant women.

There are, however, enormous financial, regulatory, and cultural barriers to this treatment that

are exacerbated by misinformed and inaccurate news reporting. Indeed, we are aware of numerous cases in which judges and child welfare workers have sought to punish as child abusers pregnant women and mothers who are receiving methadone maintenance treatment.

Conclusion

It is deeply distressing that US media continue to vilify mothers who need and those who receive treatment for their opioid dependence, and to describe their babies in unwarranted, highly prejudicial terms that could haunt these babies throughout their lives. Such reporting, judging, and blaming of pregnant women draws attention away from the real problems, including barriers to care, lack of medical school and post-graduate training in addiction medicine, and misguided policies that focus on reporting women to child welfare and law enforcement agencies for a treatable health problem that can and should be addressed through the health care system. It fosters inappropriate, punitive, expensive, and family-disruptive responses by well-meaning but misinformed criminal justice and child protective agencies, creating a reluctance on the part of healthcare professionals to recommend and offer the services that evidence clearly indicates are best for their patients.

We would be happy to furnish additional information, including references to research material discussed. Please feel free to contact Dr. Robert Newman (rnewman@icaat.org), who will coordinate response to such requests.

Sincerely,

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Abstract:**Background**

Infants exposed to intrauterine drugs present a number of challenging features with which the new mother is faced. They can be irritable, unresponsive, and unpredictable. Available treatments require specialized neonatal care for the first four to six weeks of life; a critical time for the parent-infant attachment relationship to develop. Neonatal nurses have the opportunity to promote this development and ameliorate the effect of other developmental risk factors the baby is likely to experience.

Objectives

The aim of this study was to explore neonatal nurses' experiences of providing care to drug-exposed newborns and their parents throughout treatment for neonatal abstinence syndrome (NAS).

Design, Setting and Participants

This study used interpretive methods by conducting group interviews with eight neonatal nurses in each of four Special Care Nursery Units in South-East Queensland, Australia.

Results

Barriers to promoting the parent-infant attachment relationship were found to be both attitudinal and organisational. These barriers were significant, and were seen to impact negatively on optimal care delivery to this vulnerable population.

Conclusions

Unfortunately, the results of this study indicated that management of these babies and their parents is compromised by a range of attitudinal and organisational factors.

There is a need to address these barriers to optimize care delivery and improve the way in which neonatal nurses impact on parent-infant relationships.

Keywords: Neonatal Abstinence Syndrome, neonatal nursing, parent-infant attachment, drug-dependent parent.

What is already known about the topic?

- Strengthening the parent-infant relationship and promoting potential skills of parents are crucial to mediating the adverse care-giving environments into which drug-exposed newborns will be discharged
- Attitudes towards and knowledge gained in caring for drug-exposed infants and their parents influence nurses' ability to provide such optimal management

What this paper adds

- This analysis demonstrates that neonatal nurses' care of drug-exposed infants and their parents in the special care nursery is compromised by attitudinal and organisational factors
- There is a need to address these factors to optimize care delivery and improve the way in which neonatal nurses impact on parent-infant relationships.

Background:

Specialist neonatal nursery staff caring for infants exposed to illicit drugs before they are born have an opportunity to influence adaptation to the parenting role and quality of the attachment relationship parents have with their newborns. This window of opportunity can exist for up to six weeks after the birth depending on treatment outcome for Neonatal Abstinence Syndrome (NAS).

This opportunity is critical. The parent-infant relationship can ameliorate the effect of environmental risk factors such babies are likely to experience once discharged. Unfortunately, management of drug-dependent parents and their newborns may be compromised by a range of factors^{1,2}.

This study used group interviews with four (4) groups of eight (8) neonatal nurses to explore experiences of managing drug-exposed newborns and drug-dependent parents to provide insights into the way in which effective care can be delivered. This study targeted an important clinical and public health issue. Infants of drug-dependent parents are at increased risk of physical and psychological disadvantage due to the environment into which they are born.

Literature Review:

Infants treated for NAS may require prolonged treatment and spend several weeks, or even months, in hospital³. A constellation of symptoms may result from opiate withdrawal manifesting as a disruption of the mother-infant relationship, sleep-wake abnormalities, feeding difficulties, weight loss and seizures. Current treatments that are used to ameliorate symptoms and reduce morbidity rates include opiates, sedatives and non-pharmacological treatments⁴.

The proportion of infants treated for NAS continues to rise both in Australia and overseas despite changing patterns of drug use⁵. In the United States, more than 1.4 million women of childbearing age regularly used opioid derived substances such as heroin, analgesics and methadone⁵. It has been estimated that current drug use among families with dependent children in Australia corresponds with rates reported overseas⁶. The rising incidence and changing patterns of illicit drug use in Australia extends into the population of women of childbearing age. Escalating use of psycho stimulants in particular for which we have few treatment options demands an urgent

response from health services including those providing specialised expertise in the perinatal period⁷.

The ability of drug-dependent parents to adequately care for their babies is compromised by factors clearly associated with substance abuse such as psychopathology, depression, antisocial personality, and family violence⁸. Moreover, drug-dependence continues to be more prevalent among mothers living in poverty. Parents with drug problems are vulnerable to both acute and chronic poverty and poor employment opportunities⁹. Children raised in such adversity are at increased risk of neglect and other forms of child abuse, as well as maladaptive development and behaviour problems, particularly in the early years of life¹⁰.

The effects of prenatal exposure to maternal substance abuse on negative birth outcomes have received much research attention. Fewer studies have been concerned with the attitudes of professional caregivers, particularly nurses, towards drug-dependent parents in the perinatal period and their impact on infant outcome¹¹.

Mothers using illicit drugs during pregnancy can experience profound guilt concerning the damage their behaviour has had on the infant¹². When these vulnerable mothers are paired with irritable infants withdrawing from drugs and experiencing NAS, an understanding and supportive environment is required¹².

Enhancing interaction between substance abusing mothers and infants affected by NAS was explored in a 1998 study¹² which determined whether teaching comforting and interacting techniques within 24 hours of delivery would improve the mother/infant interaction following discharge. The treatment group in this study showed a significant improvement in enhanced interaction at follow up. Nurses, it was concluded, were pivotal to the success of this enhanced interaction by

demonstrating care-giving behaviour and assisting the mother to recognise and respond to their infants' behavioural cues.

The attitudes and knowledge of nurses towards caring for drug-exposed infants and their parents is pivotal to the success of promoting attachment. In a study of cocaine-exposed infants and their mothers¹, the attitudes of nursing staff were found to be generally negative, and this impacted adversely on quality nursing care. Nurses have been reported to consider drug-dependent parents to be at least partly responsible for their own illnesses¹³ and a patient history of drug use is associated with nurses' negative attitudes, reducing their willingness to interact with these parents^{14, 15}. Nurses are also reported to embrace attitudes that are considered more punitive and negative than positive or supportive toward women who abuse drugs during the antenatal period¹⁶. Interestingly, Ludwig et al observed that providing in-service and self-education to nursing staff correlated positively with attitudes towards the infants, but not necessarily towards their mothers^{1 17}.

In researching the broader nursing communities' knowledge, attitudes and beliefs about substance abuse, Happell et al¹⁸ recommended that specific educational programs must be introduced to enhance nursing skills and therapeutic relationships in assessment and management of drug-related disorders. Nurses' attitudes towards patients influence the ability to develop and maintain therapeutic relationships that are central to the suite of nursing interventions required to promote parent-infant attachment relationships.¹⁹.

Methadone administration during pregnancy remains controversial so it is important that nurses caring for the infants of women in treatment create a non-punitive environment that is conducive to behaviour change. Specialist neonatal

nurses have great potential to influence behaviour, yet negative attitudes and values towards the substance-dependent mother have been identified as barriers to successful substance abuse treatment during the perinatal stage⁵.

Method:

Aims of the study

Thus, the aim of our study was to explore the experiences reported by neonatal nurses when providing care to infants of drug-dependent parents in the immediate postnatal period. The study was approved by the Queensland University of Technology Human Research Ethics Committee. Ethics approval was also gained from each of the four health service districts where the research was conducted.

Sample

A purposive sample of eight participants from each of four (4) special care nursery (SCN) units in South-East Queensland was recruited to the study. Participants were therefore experienced in the care of drug-exposed neonates experiencing NAS and their drug-dependent parents.

The potential for variation in clinical experience and exposure to drug addicted parents of nurses working within the SCN units was considered. We thus recruited from across a range of demographic and socio-economic districts in South-East Queensland, choosing four (4) SCN's allowing for a range of confirmatory and contradictory responses and experiences.

Data collection

Semi-structured, open-ended, interview techniques were used. Interviews lasted for one hour and guideline questions were not asked in either a sequential or prescribed manner. Questions were generated from cues given by participants to explore attitudes

and perceptions raised within the groups. These were prompted by the guideline questions. The interviewer who then developed the questions further according to the findings of the completed interviews transcribed each interview immediately. A research assistant experienced in both neonatal nursing and group interview moderation conducted the four group interviews within a two month period.

Participants were informed in writing of the study details prior to conducting the group interviews. Each participant was asked to sign a consent form to indicate that they understood the nature of the research. Group interviews were conducted during professional development time paid for by the organisations.

At the commencement of the group interview, the study was briefly explained, and confidentiality and consent was explained by the Facilitator. Participants were asked to sign an attendance sheet, identified only by their first names, which were removed during the transcription process. All participants gave written informed consent and agreed to the audiotaping of interviews. No participant withdrew from the study.

Data analysis

Verbatim transcription of interviews was conducted immediately following each group interview. Thematic analysis was completed by firstly reading and rereading to gain an understanding of the fabric of the content. Next, the transcripts were analysed to identify significant concepts, statements and feelings expressed. These were then clustered into five themes²⁰.

Results:

Five themes were generated from the data:

The themes related to:

- The relationship with the baby;
- Response to the family;
- Tensions within the care environment;
- Nurses needs; and
- Making a difference.

Relationship with the baby

Participants spoke of caring for babies affected by abstinence syndrome as time consuming and difficult. Emphasis was placed on nursing assessment using scoring systems^{21, 22}, which are commonly used to score the severity of the symptoms of withdrawal, and balancing treatment regimes to ensure babies were comfortable. The babies were described as unsettled, crying and requiring supported care. The time needed to care for these babies and the need to acknowledge the acuity was highlighted by a number of participants, for example:

‘...they’re very time consuming, and I do think we need to share the (work) load around, and so when someone’s had enough, it’s okay to say, “it’s your turn now”.’ and

‘I just think that sometimes the acuity needs to be re-evaluated because we usually have up to four babies each, but sometimes when a baby is very, very unsettled someone can use a whole shift maybe for that baby, and sometimes we need extra staff.’

The use of volunteer helpers was mentioned as a way of providing comfort measures, and potentially lessening the impact on nursing time. Use of a volunteer

service, or so-called ‘cuddle mums’ was seen as a useful addition to the care regime for these babies. Yet this service, though available previously, was under-utilised and perhaps fraught with legal implications that had not been addressed.

Interestingly, discussion that related to caring for the baby was focused on the time taken and the behavioural response of the baby to withdrawal, as well as issues impacting on work load and the demand placed on nursing time. Conversely, there was little discussion that related to general infant care issues such as feeding and hygiene provision indicating perhaps heightened concern relating to organisational issues.

Response to the family

The findings suggest that no formal family assessment was conducted, and participants often seemed uncertain about the family environment, in particular the environment into which the babies would be discharged. These uncertainties, and fear of the unknown were significant issues in this discussion.

Participants described families as ‘chaotic’ with a wide range of emotional, social and practical support needs. That participants felt substance abusers were a ‘demanding client group’ is echoed within the literature¹¹. Frustration was felt when parents did not visit often and were perceived as not being emotionally and/or physically available for their baby. A participant suggested that:

‘...I think they plan their visits. Sometimes I feel they do, because they’re not really there often enough, or for a long enough period, to really see that the baby is upset.’

However, others attempted to explain the situation:

'I think their personalities, where they are a little fragile, um, its not conducive to looking after high-risk babies. These babies just incessantly cry, and my perception is that sometimes they're just scared off because they're such hard work. It would be hard for anybody to cope with these babies who are crying 24 hours a day.'

Participants spoke of feeling 'out of the loop' regarding the care of the family. Tension seemed to exist between the role of the social worker, Department of Child Safety, medical officers and nursing staff in that while the family was intensively assisted, the nurses role in this area seemed minimal. Being 'out of the loop' in terms of communication about the family, meant that participants were not part of the care planning. In relation to this, participants seemed to be unaware of the details of maternal drug use and did not have access to this information, with assumptions being made of their drug use and the impact this may have on the baby. There was recognition of the need to communicate effectively with the family, and reference to the reluctance of mothers to disclose their drug history. Alternatively, a participant discussed the value of open and honest communication and how this would positively impact upon patient care outcomes:

'The other side of it is as well, that often, the mum's themselves are quite open about it, their drug use, and they'll talk quite openly in front of the other parents that they need to go and get their methadone. And I encourage them to tell us the truth. That it's important for us to know if they're using, and that they've been using. So that they know it will make the withdrawal for their baby more difficult, and if you do go and do that, of if you have been using more than opium drugs, then we need to know that, because the baby may withdraw differently, or you know, a lot worse.'

These findings suggest that care provision for the parents and the baby occurs in parallel rather than in partnership, a situation highlighted by one participant as being a tension between providing a family centred approach to care and focusing on the babies' needs. One participant discussed the difficulty of a family centred approach when dealing with the baby:

'You see, philosophically, we have family centred care...Which is an important thing to have, ...but it is really the baby that is our client. And trying to marry the concept of let's nurture this family to be the best family they can be, and, this child is my client. What's going to happen to it? And marrying these two ideas can sometimes be a pretty rough road.'

Tensions in the care environment

As well as a lack of time, staffing was discussed as an issue in providing care to this patient population. In particular, staff shortages adversely affected the relationship between the parents and the nursing staff. Staff shortages were frequently back-filled with casual staff, who did not know the history of the parents, and the parents were constantly having to recount their stories. This frequently lead to frustration for both parents, for example, as one participant commented:

'I've worked in SCN for some years and during that time I've seen many babies come through and often it can put a difficult stress on the unit itself due to staffing as well as the needs of these babies because often they are with us for quite some weeks and have ongoing needs, more than we feel we can support sometimes.'

And

‘Yeah, that’s too hard with our staffing, they’re always having to get used to a different face and having to tell their story all over again, when they have gotten used to somebody, and are feeling comfortable and not judged.’

The relationship between medical officers and nurses was discussed in particular in terms of assessment and the ordering of medication. Participants stressed the need that their assessment skills be recognised and respected by the medical staff. They were, after all, the primary care providers and worked with the babies and their parents on a shift-by-shift basis. Overall, however, participants stated that for the most part, their assessment of the baby was listened to.

The inclusion of the nurse as part of the multidisciplinary team caring for the baby and his/her family did not extend to social workers and community providers, however. Participants expressed concern that they did not receive feedback about what happened to the baby following discharge. For example a participant discussed her lack of experience:

‘And I think there are significant child safety concerns, my barrier is inexperience of child safety when we’re often discharging these babies into an unsafe environment, unknown, and we’re making significant life changing decisions on behalf of these babies, when we know that a significant number of these babies have our alarm bells ringing. So I think my barrier is the lack of networking, and back-up and infrastructure within the community.’

And

‘The social workers just say “she’s got a great support mechanism out there”, and you go “well, what’s a great support network?!” Because I don’t know

what that means exactly. Does that mean somebody checking on her, somebody driving her, what does that mean? It's all a bit nebulous.'

Heightening the tensions within the care environment was discussion about whether the environment of the special care nursery was the optimal environment for these babies and their parents. It was generally concluded that the physical environment was not conducive in terms of privacy and disruption caused by a constantly crying baby. For example in describing the environment participants suggested:

'But I think too, I know if there are people in the room, you know, during the doctor's rounds I try too do a little charade quietly, or just point to something for the doctors to see so I don't have to say 'this baby's withdrawing'. But, they'll often, you know, let the cat out of the bag. So that is hard, because they're... you don't know how to be discreet really.'

Participants, therefore, were asked about what they felt the optimum environment for these babies and their families actually was. Suggestions include:

'Err, I think there should be a centre geared up for this, because you need a key little group that monitor these babies. I know that at X in X they communicate closely with them when they go home, whereas we just send them home, sometimes on fairly significant doses of morphine and there's concern amongst the nursing staff because these families really aren't at the

point where they can monitor or look after their babies. And yet, we leave them to it.'

And

'But it's the biological perspective as well, these mothers and babies are separated for a long time. And, um, the system isn't necessarily assisting them in any way. They have a tendency not to stay anyway, to go out and about, but, maybe if we had more rooming in rooms, and a little bit more flexibility with morphine in terms of having a unit where they could stay it might help in the long term, to keep these mothers and babies together.'

Nurses' Needs

The emotional work involved in caring for NAS babies and their families was recognised, and strategies for distancing themselves from the situation were discussed, as one participant suggested:

... I mean, I don't get that emotionally involved. That's why I can stay in this profession. I do what I have to do, I say what I have to say. I mean, you have to do that... otherwise you just get far too involved with these poor little babies, knowing that they're going to go into a household... You can't stop them going home with these parents.

It is not surprising that nurses working with potentially emotionally charged situations need to develop coping mechanisms, or some form of emotional control or protection. This tendency to emotionally protect oneself may be justified, with Yang & McIlpatrick²³ reporting that more than half of the nurses in their study experienced

profound feelings of sadness or loss following critical incidences and volatile situations, such as death or stress in working with families, within the work environment.

Participants recognised the importance of education and preparation in the areas of communication and counselling but also discussed the need to understand the physiology related to NAS. Importantly, one participant articulated the need to understand the background to substance abuse and acknowledged the impact of her own background on her knowledge in this area:

'You really need to know how to word your questions, and all that sort of stuff, that's what you need more training in... you know, the psychology of how to present yourself to these people. But being able to ask the right questions in the right way you can get more information out of them. Because, you don't want to build a brick wall. You really do want to know, and I think that's the hardest part. We need them not to necessarily be able to trust you, but to tell you what you need to know to care for their baby. But also to have some regard for us as well, as people but they see us either as dragons or these people that are going to take their baby away.'

And

'...understanding why these people get themselves into these situations in the first place understanding the background problems. I dunno if that makes sense, but you know, I don't know how to counsel these people... And I lack the knowledge and the skills to deal with these types of people. I work in the

clinic, and they tell you these stories and I think “okay where’s the social worker!””

When asked if the stress of working with these families was assisted by formal or informal debriefing, the majority of participants agreed that informal debriefing within their peer network was beneficial, with less importance placed on the opportunity for formal debriefing.

‘I really can’t see how an outside debriefing could be anymore beneficial than the network we’ve got here. We utilise our own network regularly, we have high levels of stress because we’ve got a lot of crying babies who are going through withdrawal, and it is difficult on the staff, and we try to say ‘I’ve looked after this baby for two days, and I need a break’, and we often, you know, vent our own frustration, particularly at handover times, or in private. And I think that’s a far better network because we’re talking to our peers, who understand.’

Discussion regarding the nurse passing moral judgement on families with babies experiencing NAS was met with mixed reactions, but generally, findings from this study reflect the literature, in that the attitudes of nurses towards substance abusing mothers was generally negative and judgemental¹⁷

‘We talk about judgement, and yeah, we do (judge them). We don’t mean to, but you just do, and the parents think, ‘well the babies gone to the nursery, and its started on medication, and I’m gonna be worried that I never get this baby

back'. And I think the reality of that is that there are people and families who think they are judged. And they are judged!'

When asked how staff demonstrated such judgemental attitudes a participant suggested that it is: 'Just their body language. Perhaps they are condescending. Just the way they behave towards the parents. Or they don't want to speak to them'.

Judgemental behaviours towards this client population have been demonstrated previously, where it has been reported that attitudes towards women who abuse substances were more punitive and negative if they continued to abuse during the perinatal period¹⁶.

Making a Difference

Nursing staff were asked how delivery of care could be improved to this disadvantaged population, and what the organisation could do to support this. Suggestions of the staff focused primarily upon targeting these parents antenatally, and providing support to nursing staff in terms of professional development. A lack of ongoing education in this area was cited as a significant barrier by participants.

Pre-admission, or ante-natal education, was cited as an opportunity to interact with substance-abusing parents in order to prepare them for what to expect once their baby was delivered. This education, and facilitated familiarity with nursing staff and the organisation, was suggested as an opportunity to positively impact upon parents, and improve care delivery in the post-natal period. For example one participant suggested that:

'I think that at times we have made a difference. I mean, I think the whole thing of nursing with these babies is we need to have a certain amount of empathy, and we need to be non-judgemental. If we can accept the parents and where they are, the bottom line is that we are the baby's advocate, we can still try and be as non-judgemental as possible with the mothers, come down to their level, and get an honest, open communication going so A) they share what knowledge, or information they need to with us, and B) this can be used as an avenue to, you know, to link them into social work etc. It's not always a positive situation, but quite often they don't see nursing staff in a negative light, and have an honest, open communication and rapport and can utilise us, um, you know, for information, helping with their parenting skills and usually the majority treat us very favourably, and we do have a good rapport though not always.'

Discussion:

This study explored nurses' experiences of caring for drug-exposed newborns and drug-dependent parents in an environment providing specialised care. It identified barriers to effective and appropriate caregiving from a range of perspectives. Widespread use of illicit substances extending to populations of childbearing women imposes substantial social and economic costs across health, welfare and criminal justice systems. Infants born to substance dependent parents require highly specialised nursing care due to the physical and biological effects of substance exposure during pregnancy.

Moreover, nurses play a key role in creating a positive social environment for infants born into adversity. The newborn period presents an opportunity to influence

the parent-child relationship which mediates high-risk care-giving environments into which these infants are born. This is a time when the underlying parental commitment and potential skills of parents are influenced.

Within the realms of this potentially therapeutic relationship, the importance of nurses' attitudes towards disadvantaged client populations needs to be recognised as influencing one of the cardinal elements of the nursing profession¹⁹. Furthermore, the results of a 2003 study¹⁷ with neonatal nurses caring for infants affected by substance abuse revealed that there is a need for formalised education on substance abuse and its affects, and that this may positively impact upon nursing attitudes.

Conclusion:

Unfortunately, in this study, neonatal nurses identified that they experienced significant barriers to providing quality family centred models of care to drug-exposed infants and their parents. The results support the development, trialling, and dissemination of an intervention aimed at early intervention and risk reduction to enhance care in this disadvantaged patient population. Such an intervention would target both the attitudinal and organisational issues raised. Intervention strategies could include awareness raising workshops for nurses working in SCN units, as well as organisational change management strategies considering how, where, and by who these infants could best be cared in the immediate post natal period for example.

Facilitation and support staff in healthcare environments attract a range of assistive professional skill sets. Challenging environments such as those featuring babies with NAS and high risk families however, are typically beyond the base training of most nursing staff and require appropriate responses from both the individual clinician and the support organisation.

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The Opioid dependent mother and newborn dyad: non-pharmacologic care

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Abstract

Opioid dependent pregnant and post-partum women and their infants are a complex and vulnerable population requiring individualized, comprehensive and multidisciplinary treatment. Though methadone maintenance in the setting of comprehensive service provision during pregnancy significantly improves pregnancy outcomes for opioid dependent women, its use has implications for the infant, most notably the Neonatal Abstinence Syndrome (NAS). NAS is comprised of physiologic signs and behaviors that indicate a dysfunctional regulation of the central and autonomic nervous systems, and is variable in its expression in affected infants. The disorganized rather than adaptive behaviors displayed by each infant undergoing the effects of in-utero opioid exposure may impair basic functions such as feeding, sleeping, and the ability to be alert and communicate clear cues to caregivers. Understanding and responding to neurobehavioral dysfunction of the newborn may help to promote the infant's self-organization and self-regulating abilities. However, the substance abusing mother's physical and psychological wellbeing may be debilitated in the perinatal period, and her ability to recognize and respond to the newborn's cues may be limited. A multi-tiered comprehensive assessment and intervention of the methadone-maintained mother, her child, and the mother/infant dyad can improve early maternal nurturing interactions, a crucial component of early infant development, particularly in this vulnerable population. The purpose of this article is to review the contribution of maternal opioid dependency to the difficulties experienced by the mother-infant dyad and their treatment providers in the postnatal period, and the non-pharmacological treatment of the infants with suggestions for practical measures with emphasis on the treatment of the mother and baby as an interactional dyad.

Keywords

Neonatal Abstinence Syndrome; methadone; substance abuse; opioid; infant

Introduction

The infant with NAS and his mother present a complex and frequently difficult dyad to adequately assess and treat. Nearly all opioid exposed infants will display symptoms of Neonatal Abstinence Syndrome (NAS)⁽¹⁾, however, only a subset require pharmacotherapy⁽²⁾. Non-pharmacologic care of the opioid exposed newborn refers to the careful evaluation of the infant and his mother, provision of nursing/caregiving interventions, and modification of the environment and social interactions that support his/her neurodevelopmental and physiological stability. Non-pharmacologic care is not intended to substitute for pharmacologic treatment of those infants requiring medication but should be the standard of care for all infants at risk for NAS. An essential component of non-pharmacologic care is the education and facilitation of maternal involvement with the infant.

Each infant displaying NAS has a particular level of maturation and style of processing and responding to environmental stimuli and caregiver's cues, contributing to the variability of

expression of NAS. Infants display different NAS symptoms with different intensity over time. Therefore, appropriate supportive care of the in-utero opioid exposed infant requires a thorough examination and accurate identification of the individual physiologic and behavioral expressions of NAS in each infant, triggers of its symptoms, and an individualized plan to modify the environment and caregiver's interactions. These signs can be difficult to interpret in a dysregulated newborn experiencing NAS. In addition, although the substance dependent woman frequently wants to understand and help her newborn, she may lack the training or emotional ability to recognize the behaviors of her baby and support the infant's efforts to become stable and well-organized.

There is sparse empirical literature regarding the non-pharmacologic care of drug exposed neonates. Interventions that have been reported to support neurobehavioral functioning in drug exposed neonates, but not systematically evaluated, include swaddling, the provision of a quiet environment and pacifier use^(3,4,5). Most supportive care plans for neonates with NAS are regarded as standard (e.g; swaddling, small feedings, pacifier), regardless of the infant's individual functional and developmental characteristics, capacity for NAS expression and self-organization. Waterbeds have been reported to improve neurobehavioral functioning in opiate exposed infants⁽⁶⁾; conversely, rocking beds have been shown to increase withdrawal symptoms in this group⁽⁷⁾. An individualized non-pharmacologic care plan should seek to support the infant's autonomic, sensory, motor and interactive development based on the specific signs and behaviors displayed by the infant. The infant's behaviors will determine the modifications of the environment, the specific comforting techniques needed and the consolidation of patterns of activity, timing for nursing interventions, feeding and rest. Also necessary in optimal care of the infant experiencing NAS is an assessment of maternal well-being as well as what the newborn is receiving from her that promotes or impedes his neurophysiological functioning and developmental progress. The population of opioid exposed infants exhibit many characteristics found in infants with regulatory disorders⁽⁸⁾, and other high risk populations, including cocaine exposed infants and preterm infants. These characteristics, which include dysfunction in autonomic regulation, sleep/wake control, motor, attentional/interaction and self-regulatory systems, have been previously well defined in these populations⁽⁹⁻¹²⁾. Therefore, the parenting/supportive strategies applied in the care of other high risk populations have been applied to the opioid exposed newborn in this review of non-pharmacologic interventions. The purpose of this paper is to provide an overview of the opioid dependent mother and her contribution to the infant's neurobehavioral profile, as well as practical guidelines for health care providers for the assessment and non-pharmacologic treatment of methadone-exposed mother-infant dyad. The discussions and recommendations provided will assist health care providers with: 1) recognizing the behaviors and physiological signs exhibited by the individual newborn undergoing NAS, 2) responding with techniques that positively affect the newborn's neurobehavior, organization and maturation, 3) better understanding of the needs of the complex population of opioid dependent and methadone maintained postpartum women and 4) viewing the opioid exposed infant as one aspect of a dyad and the need for simultaneous treatment of both the infant and the mother.

The opioid dependent postpartum woman

Addiction is a chronic disorder of the brain that can result in highly complex behavioral symptoms driving destructive choices and actions in substance dependent mothers, many or all of which have direct implications for the well-being of the infant. At the core of addiction there is a compulsive and uncontrollable drug craving, seeking and use^(13,14). The mother loses ability to control her life, rearranging her motivational priorities and putting drug-seeking and drug-taking behavior as a life priority at the expense of most other activities, even when faced with negative consequences, such as the loss of child custody, or continuing use when the drugs do not produce pleasurable effects⁽¹⁵⁾. There are several factors that increase the risk of

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addiction, including biological (genetic, gender, mental disorders) factors, environmental (chaotic home, abuse, peer influences, etc) factors, and characteristics of the drug itself (type of drug, route, early use) (16, 17) (Figure 1). Therefore, each chemically dependent mother brings to the dyad her own capabilities to care for the newborn depending on her developmental history, addiction severity, comorbid disorders and support system. It has been suggested, for example, that mood disorders and substance abuse might hijack the mother's motivation and reward systems, and alter infant-related reward perception and salience (18). This in turn may interfere with maternal self- and mutual-regulation of affect (19), maternal responses, mother-infant attachment, and thereby infant/child development.

The most effective treatment for opioid dependent pregnant women simultaneously provides pharmacological (i.e. methadone), behavioral and social services interventions (20,21,22,23). Methadone maintenance offers clear benefits to the pregnant/postpartum woman, including improved health care, reduced infant mortality (24), decreased illicit opiate use (25–27), improved substance abuse treatment retention (28) and stabilization of chaotic environments and behaviors by reducing drug seeking behaviors such as prostitution (23). However, methadone treatment is only one component of the multi-tiered and comprehensive treatment approach for this population of women. Pregnant and postpartum women receiving methadone need specialized assessment and treatment for psychiatric problems, mental health counseling to include individual and/or group therapy, and intensive social support (to include financial, legal, housing, child welfare and domestic violence services). Women receiving comprehensive care of this nature during and after their pregnancy are more prepared to deal with the physical, emotional and maternal demands of the perinatal and postpartum periods. Pain control, requirements for changing methadone dosing and physical fatigue in the immediate post partum period need to be differentiated from fatigue related to demands of the care of the baby, postpartum depression or relapse. These conditions may interfere with the ability to respond properly to the infant and to provide nurturing interactions, and each woman should be evaluated for each of these conditions. Health care providers in different settings providing care to the mother/infant dyad are in an ideal situation to assess and advocate for the mother and the infant. Risky behaviors detected in the mother during the postpartum period (i.e.; sedation, signs of relapse, postpartum depression) need to be assessed by any provider involved with the dyad. After a non-judgmental direct observation of the mother, mother/infant dyad and exploration of the maternal status with her substance abuse treatment counselor, a decision about the maternal post partum care plan and neonatal care plan in tandem should be formulated. Unfortunately, deeply held cultural beliefs and negative stereotypes frequently result in punitive responses toward the opioid dependent pregnant and parenting woman by the providers who are most poised to positively impact the mother and child (29–30).

The opioid exposed mother/infant dyad

Research during the last decades supports the notion that the infant's relational experience with the environment and caregivers during the first years strongly influences the neuroanatomical (brain organization, hardwiring of sensorimotor pathways) and physiological (brain bioamine metabolism) development (10). The infant's behaviors, including hypertonicity, tremors, facial expressions, cry and, state control influence the behavior of the newborn's caretaker (31). These behaviors can be challenging, especially for the opioid dependent mother, and difficulties in the dyadic processes of regulation may lead to altered developmental and interactive trajectories in the infant (32). Multiple factors affect the mother's emotional and physical availability to help regulate and organize her newborn when exhibiting NAS. First, methadone maintained women frequently find it particularly emotionally difficult to see their newborns displaying symptoms of NAS related to methadone exposure. Maternal guilt and anxiety, insecurity about her ability to parent due to poor parental role modeling, the loss of other children and a lack of self-esteem are common among this population of women. If in addition

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she lacks the ability to recognize these feelings, modulate them, and take the appropriate actions on behalf of herself and her child, maladaptive behaviors such as relapse, aggressive behaviors with relatives or health care providers, and/or neglect of the baby may be the outcome. Second, partners, relatives and occasionally health care providers seeing the newborn with NAS overtly or covertly blame the mother for her drug dependency and/or receiving methadone during pregnancy, increasing maternal distress or precipitating abusive or violent confrontations. Third, it has been suggested that maternal substance abuse, mood disorders and adverse childhood experiences may influence maternal responses to newborn cues^(33–35). Distorted interpretations of the infant's signs based on her own mental working models (what the mother thinks and feels about herself and her newborn) lead the mothers to characterize their newborns as "good", "difficult", "stubborn", "gassy", etc. based on their behaviors. These interpretations drive maternal responses that can impact the organization of the infant and initiate developmental trajectories that can promulgate behavioral, emotional or interactional problems. Finally, the above factors or symptoms of maternal mood disorders may affect maternal responses to the baby and in turn his organizational capacity. For example, depressed mothers may have difficulty tolerating infant irritability or may have trouble finding the energy to appropriately stimulate a newborn that displays low arousability or difficulty with interaction^(36,37). Mothers with uncontrolled symptoms of anxiety or ADHD can be loud and intrusive, and their handling of the baby too vigorous for an easily overstimulated infant.

By examining the newborn in the presence of the mother, the provider can demonstrate the range of the infant's physiological and behavioral competencies and weaknesses, as well as adaptive or maladaptive responses to external stimulation. At the same time the maternal responses to each displayed newborn sign can be observed. Attention to maternal reactions and behaviors can direct the intervention with the dyad to diminish emotional overload and provide external organization until the infant can develop higher sensory limits and consistent behavioral self-regulation⁽⁹⁾. Helping the mother to be aware of her emotions, behaviors driven by those emotions, and her capacity to regulate them may improve her ability to respond to the infant and thereby the mother infant interaction^(38–40). It is necessary to address maternal perceptions of the newborn's condition and cues (realistic vs distorted), behavioral patterns, and responsiveness to external and internal stimuli. This in turn may lessen or ameliorate emotional and developmental problems in the baby, facilitate mother-infant interaction and decrease the risk for abuse or neglect.

The opioid exposed infant

Each newborn has a rich and complex set of behaviors for regulating his internal states and interactions with the environment⁽³¹⁾. NAS can be seen as a group of physiological signs and behaviors that indicate a dysregulation of the newborn's behavioral repertoire and functioning⁽²⁾. Using a model adapted from the Synactive Theory of Development⁽⁹⁾ as a framework to conceptualize the assessment of the infant's functional repertoire and ability to regulate his responses, the following infant's neurobehavioral domains are critical to a comprehensive assessment of the infant with NAS: 1) reactivity to sensory stimulation, 2) behavioral states and state regulation, 3) motor and tone control, and 4) autonomic signs of stress. Individual NAS symptoms are a product of dysregulation of one or more of these domains, and the NAS expression varies based on the infant's capacity in each of these areas. These domains are interrelated and influence each other, as are the variety of signs and behaviors expressed by the infant. Dysregulation in one or more of these domains may interfere with basic neonatal functions such as feeding, sleeping, growth, emotional regulation or social interaction (figure 2).

Reactivity to sensory stimulation and regulatory issues

“Sensory processing” or “sensory integration” refers to the ability to take in information through each of the sensory systems (visual, auditory, tactile, vestibular, and proprioceptive), process and organize that information, and give meaningful motor, attentional, and emotional responses according to the stimuli. Infants who struggle to integrate sensory input become overwhelmed by regular sensory signals such as lights, regular sounds, touch, movement and internal body signals, which may hamper the newborn basic functioning⁽⁴¹⁾. Each newborn with NAS has a unique profile of responses to sensory stimuli, but very frequently displays non-adaptive responses that suggest deficits in the nervous system’s ability to receive, filter, organize, and integrate stimulatory input. For example, infants undergoing NAS with a high level of reactivity, can respond to regular caregiver initiation of social interactions such as eye contact, voice or light touch with irritability (vocal or non vocal), erratic movements of the limbs, or signs of stress such as spitting up, bowel movements, hiccups, etc. Other infants may become quiet, close their eyes, and ignore any sensory stimulation (pull down). These difficulties with self-regulation of sensory input make the infant appear over-responsive or under-responsive.

Behavioral states and state control

The newborn’s sleep-wake states indicate both his own endogenous regulatory processes and the effects of exogenous influences from the environment, and are traditionally defined as a distinct group of physiological signs and behaviors, ranging from deep sleep, quiet sleep, drowsy, quiet awake, active awake, to crying. The expression of behavioral states reflects the infant’s nervous system maturity and neuroregulatory capacity^(12,42). Opioid exposed infants may not be able to achieve the entire range of states, may have difficulty managing the transition between various states, and/or spend larger amounts of time in one state (i.e.; crying or somnolent). These infants move quickly from state to state (i.e.; asleep to crying) with little cueing, which is termed state lability. They may display sleep deprivation (reduction in the percentage of sleep state compared with controls), disorganization (increased amount of sleep in indeterminate sleep or sleep that does not meet criteria for quiet or active sleep), and fragmentation (more shifts from sleep to wakefulness precipitated by arousals)⁽⁴³⁾.

Behavioral states influence many aspects of the neonatal neurobehavioral functioning⁽⁴⁴⁾ with each behavior occurring primarily in a specific sleep-wake state. For example, among non drug exposed infants, jitteriness is seen more in those who are sleepy or active and least frequently in infants who are in a quiet alert. Furthermore, the severity of some behaviors can be defined by its presence in a particular state. For example, jitteriness is considered mild if the tremors occur only during sleep or crying states or after the administration of the Moro reflex, and moderate to severe when observed during quiet alert states or consistently in several states when evaluating infants experiencing NAS⁽⁴⁵⁾.

The expression of NAS symptomatology depends on the infant’s state and the infant’s ability to modulate between states. For example, infants who remain primarily in a sleep state will express NAS symptomatology differently from infants who frequently attain an insulated cry state. Neither infant may be able to achieve the quiet alert state necessary for social interaction due to a lack of ability to modulate their arousal. Newborns with poor neurobehavioral adaptational skills will protect themselves by shutting off external stimuli (pull down) to provide a barrier to stimulation in response to an overstimulating environment, even though these stimuli may be minimal. Such infants appear to be hypersomnolent or difficult to arouse. Conversely, other infants unable to adapt to environmental stimuli become irritable, fussy, and hypertonic and actively disengage from communicating; for example, by averting their faces and arching their backs when presented with eye contact. These infants may actually be in a

similar overstimulated state as the somnolent infant, and each would require different caregiver techniques to help them to modulate their arousal.

Crying is a behavior that precipitates attention from the caregiver. The crying infant requires careful evaluation to determine the appropriate response. Most frequently, crying represents the newborn's way of communicating his basic needs (diaper change, hunger, and fatigue). In some infants with NAS crying may represent difficulty in managing stimuli, or can be a hallmark of poor state regulation and difficulties with modulation of arousal. These infants cannot be easily soothed and/or cannot use self-consoling behaviors, and excessive energy is expended on maintaining physiological balance. Infant crying frequently produce maternal guilt and anxiety or potentiate postpartum depression, which may further amplify the expression of NAS or trigger abuse if the mother is impaired and unable to deal with the infant's irritability.

Motor and tone control

Infants experiencing NAS frequently display hypertonicity, exaggerated primitive reflexes (i.e. Moro), changes in tone, and/or may have asymmetric tonal changes or fluctuating levels of tone. Infants with NAS frequently display tremors, uncoordinated movements, startles and various jerky movements that can be present in all states but are more pronounced in irritable or crying states. Although tremors are the most common involuntary movement of healthy full-term infants, found in 20 to 50% of low-risk newborns, they are seen with greater frequency (88%) among opioid exposed newborns⁽⁴⁴⁾. They can be triggered by any stimuli or no apparent stimuli. These movements may produce great anxiety for the mother and family.

Another motor control problem not infrequently encountered in opioid-exposed newborns is myoclonic jerking. Myclonic jerks are abrupt, jerking movements of the extremities or face occurring during sleep states. These movements may or may not be isolated to one arm, leg or one side of the body, can involve the face and chin, and do not stop when the extremity is held. Myclonic jerking is common in opioid exposed infants and must be differentiated from seizure activity.

Suck/swallow incoordination, improper positioning of the tongue on the nipple, and poor latching to breast or bottle may be other motor derived symptoms of NAS. This can result in the infant failing to take in enough calories to grow due to inadequate formula intake or loss of formula or breastmilk from the sides of the mouth, resulting in failure to thrive. Infants with suck/swallow incoordination often produce a clicking noise and/or may take in more than usual amount of air during feeding, leading to gastrointestinal upset.

Autonomic signs of stress

Behavioral signs of stress that indicate a dysregulation of the autonomic nervous system are frequent among infants undergoing NAS. They are a reflection of difficulties in continuous regulation of this portion of the nervous system, which provides afferent and efferent (parasympathetic and sympathetic) feedback loops for the purpose of homeostasis and postnatal adaptation. This dysregulation, combined with internal and external stressors, produce symptoms frequently called autonomic signs of stress^(45,46) such as color changes, mottling, tachypnea, hiccups, gagging, spitting up, sneezing, yawning, sighs, bowel sounds, or frequent bowel movements. Vomiting and loose stools may be signs of dysregulation of the autonomic nervous system and these symptoms may be severe enough to cause the infant to fail to thrive, though not usually. These symptoms should be viewed as signs of stress and treated as such if other organic causes are ruled out, as symptoms of NAS frequently overlap. As with other infant behaviors, stress signs are state dependent. Tachypnea, for example, can only be interpreted during quiet states.

Several factors may influence the individual newborn's response to a stressor, including the type of stressor, intensity of the stressful stimulus, morbidity status, behavioral state, and infant gestational or postconceptional age⁽⁴⁷⁾. In the case of NAS it has been found that premature and full-term infants prenatally exposed to opiodes have different courses of NAS, with preterm infants having shorter lengths of hospital stay and less medication requirements than full term infants^(48,49). It is not clear why preterm infants do not exhibit similar patterns of withdrawal as term infants. Studies in behaviors among non-drug exposed preterm infants suggest that significant changes in infant behavior occur over the time period from preterm birth to 40 weeks of gestation. These changes involved the absolute percentage of each expressed behavior and the percentages of each behavior expressed within each sleeping and waking state⁽⁵⁰⁾. For example, negative facial expressions increased over the preterm period; sighs, startle/jerks, jitters, and the likelihood of having hiccups decreased. All behaviors showed state-related differences in frequency, and only startle/jerks and jitters showed the same developmental patterns within each state, leading to the conclusion that preterm infant behaviors cannot be used clinically for assessment without consideration of the state in which they occur.

Non pharmacologic interventions for infants with NAS

Reactivity to sensory stimulation and regulatory issues

In general, for hyper- or under- responsive infants the room should be quiet, with dim light, and the infant handled in a soft, slow manner using stimuli that the caretaker has determined to be manageable to the infant. In addition, specific holding/containing techniques, such as holding the newborn's hands against his chest in a supine or side position, providing firm but gentle pressure to the trunk or head, and/or swaddling frequently help the baby to better tolerate stimulation (See picture 1). Some infants who have difficulty regulating sensory input may display self-soothing abilities, such as bringing the hands to the mouth or self-clinging. Mothers should be taught the beneficial implications of the ability to self soothe. A pacifier is helpful for hypersensitive infants in both organizing a dysregulated infant and in preventing disorganization of the infant during care routines. For example, upper extremity containment and non-nutritive sucking can be useful while changing a diaper for an infant sensitive to touch, temperature change or kinesthetic stimuli.

Behavioral states and state control

Awareness of the different behavioral states and the importance of recognizing the infant's ability to regulate them, as well as the variable expression of NAS in different states are crucial. Infants that have recognizable difficulties in state control should be evaluated for their ability to transition through states in a comfortable environment with minimal, manageable stimuli (low lights, minimal sound, touch and movement) with the goal of helping them to achieve quiet alert or restful sleep. Parents need to be encouraged to respect sleep, and to wake a newborn who is in a sleep state only if feeding is needed, emphasizing the important role of sleep in brain development⁽⁵¹⁾. At the same time it is equally important to determine and provide only the amount of stimuli tolerable to the infant, with the goal of achieving a quiet alert state. Slow arousal, keeping the environment minimally stimulating, and using gentle handling prior to the time of feeding, bathing or changing (or preparing the infant for any interaction), may help the infant to achieve improved regulation between states. Infants with difficulties in eye-to-eye contact due to overstimulation may be at risk for being poorly related to their mothers. These infants require a sensitive caregiver that understands that a rested infant better tolerates interaction, and accordingly adjusts the environment to the infant and avoids any intrusive behaviors. A pacifier, gentle and slow vertical rocking, and containing the arms can facilitate eye contact and interaction. Some infants can be very sensitive to brightly colored objects. The use of black and white objects or determining which colors or visual stimuli are

comfortable may prevent overstimulation and facilitate attention and better control of neck and head movements while focusing on and tracking objects or faces.

Motor and tone control

Treatment of motor and tone dysregulation, such as tremors or disorganized motor movements and hypertonicity, includes gentle handling and containment, positioning, non-nutritive sucking and swaddling (with careful observation of infant temperature). First, the caregiver can put the baby on his side or back, hold his hands (frequently the infant grasps the handler's thumbs) and bring them toward the baby's chest. If the newborn is on his side, the head and hips can be brought forward, simulating the fetal position. In addition, very gentle pressure can be applied to the head, and/or trunk or the head rubbed gently. When holding, the provision of gentle pressure to the posterior head bringing the head forward will help if tolerated. Slow vertical rocking can be used to help with relaxation in some infants. Hyperthermic infants may not be able to be swaddled, and in these infants, a folded blanket across the chest to contain the arms may be beneficial. Fisting, back arching, jaw clenching, and/or head thrashing may be interpreted by the mother as the infant's dislike of being held. This misinterpretation can be changed by a provider that models and demonstrates techniques that relax the infant's tone and decrease the uncoordinated movements. It can be a rewarding experience for the mother to feel the calm and sense of wellbeing of a cuddled, properly positioned and contained baby. Knowing that her techniques can move the baby from a hypertonic, disorganized, irritable state to a quiet alert or sleep state can increase her self confidence. Pacifiers are very useful, in general, because rhythmic, non nutritive sucking behavior has a soothing and state-organizing effect on most newborns and helps to modulate and decrease infant uncoordinated movements and distress⁵²). However, caregivers need to be aware that infants who do not have good control of movement may vigorously turn their heads side to side (head thrashing, or exaggerated rooting) when the pacifier or nipple is brought close to the mouth, suggesting that the baby does not want them. Helping the baby to keep his head still will facilitate the insertion of the pacifier or breast nipple to the mouth. Motor difficulties such as hypertonia and tremors may produce excoriations over pressure points. Excoriations of knees and elbows may occur due to excessive movements of extremities. Attempts to get hands to mouth to self-soothe may be difficult for hypertonic and jittery infants and result in scratching of the face or body. Mittens, frequent holding, swaddling and pacifiers may help these infants.

For infants with feeding difficulties due to motor and/or tone regulation, small and frequent feeds of high-calorie formula (to compensate for excessive caloric expenditures), frequent burping, and evaluating signs of stress at frequent intervals may help, with interruption of the feed if the infant is growing tired, needs to reposition or requires self-organization or assistance with organization. Rubbing the back instead of patting (which may repeatedly set off a hyperactive Moro reflex in some infants) during burping can decrease overstimulation in hypersensitive newborns. Some infants may need the pacifier during pauses to burp if they become very irritable when the bottle is removed from the mouth.

Autonomic signs of stress

An environment that bombards the newborn with a level of information that cannot be processed effectively can overwhelm the infant's autonomic functioning and produce stress responses that potentiate the expression of NAS.

As soon as a sign of stress is detected (e.g.; hiccups, color change, bowel sound) the interaction with the infant should be modified in order to stop the sign and prevent further homeostatic dysregulation (spitting up, gagging, bowel movement) due to external demands. Infants exhibiting pull down are frequently under recognized and under treated, and they often display poor feeding and failure to thrive. Careful observation for signs of stress such as color changes,

bowel sounds, sneezing, back arching, particularly in response to stimulation, should provide some cues to handlers that the infant is awake and not in a sleep state as he may appear to be. Caregivers need to avoid vigorous stimulation, which is the natural inclination of a care provider to arouse and feed the infant. These infants should receive small and frequent feedings with gentle handling, and the environment should be minimally stimulating. Lack of autonomic regulation has been found to serve as a critical indicator of negative infant behavioral cues and decreased maternal responsiveness⁽⁵³⁾. An under- or over-stimulating environment for a dysregulated infant can impair movement toward more complex and integrated responses that facilitate the development of the cognitive, social, emotional and motor functions. Health care providers can point out how to recognize signs of stress, what triggers exist for the stress responses observed in the infant, and what to do to prevent or ameliorate them.

Conclusion

Non-pharmacologic management should be employed for every opiate exposed infant from the time of birth. The goal of non-pharmacologic intervention is to support the neuromaturation and self-organization of the infant, and it should be instituted and continued with infants displaying NAS regardless of their need for medication therapy. Non-pharmacologic treatment of NAS should not be used as a substitute for opiate replacement medication for infants that require such. It is well accepted that stable, sensitive and attuned caretakers affect the infant's regulatory capacity and his ability to establish meaningful relationships^(54,55). Challenging behaviors such as irritability, uncoordinated movements, dysregulated sleep-aware patterns, hypertonicity, and autonomic signs of stress, frequently displayed by an infant undergoing NAS, can initiate altered caregiver behaviors, which have been considered an additional teratogenic effect of the prenatal substance exposure⁽³¹⁾. The modification of NAS expression in affected infants and the infant's recovery depend on the care provider's ability to correctly interpret the infant's abilities and difficulties, the provision of individualized comforting techniques, and the avoidance of intrusive interactional strategies often used to elicit social behaviors in the newborn. Multiple factors affect the mother's emotional and physical availability to help regulate and organize her newborn exhibiting NAS. Maternal substance abuse, mood disorders and adverse childhood experiences may influence maternal responses to the newborn cues^(33,34,35,56). It is the role of the health care provider to properly assess and interpret the infant's behaviors, determine how the mother understands and responds to her infant, and to tailor interventions to help the mother provide a sense of well-being and organization to the infant and a sense of confidence in her parenting abilities. This in turn may improve the infant's short, and possibly long term developmental, behavioral and interactional outcomes⁽⁵⁷⁾.

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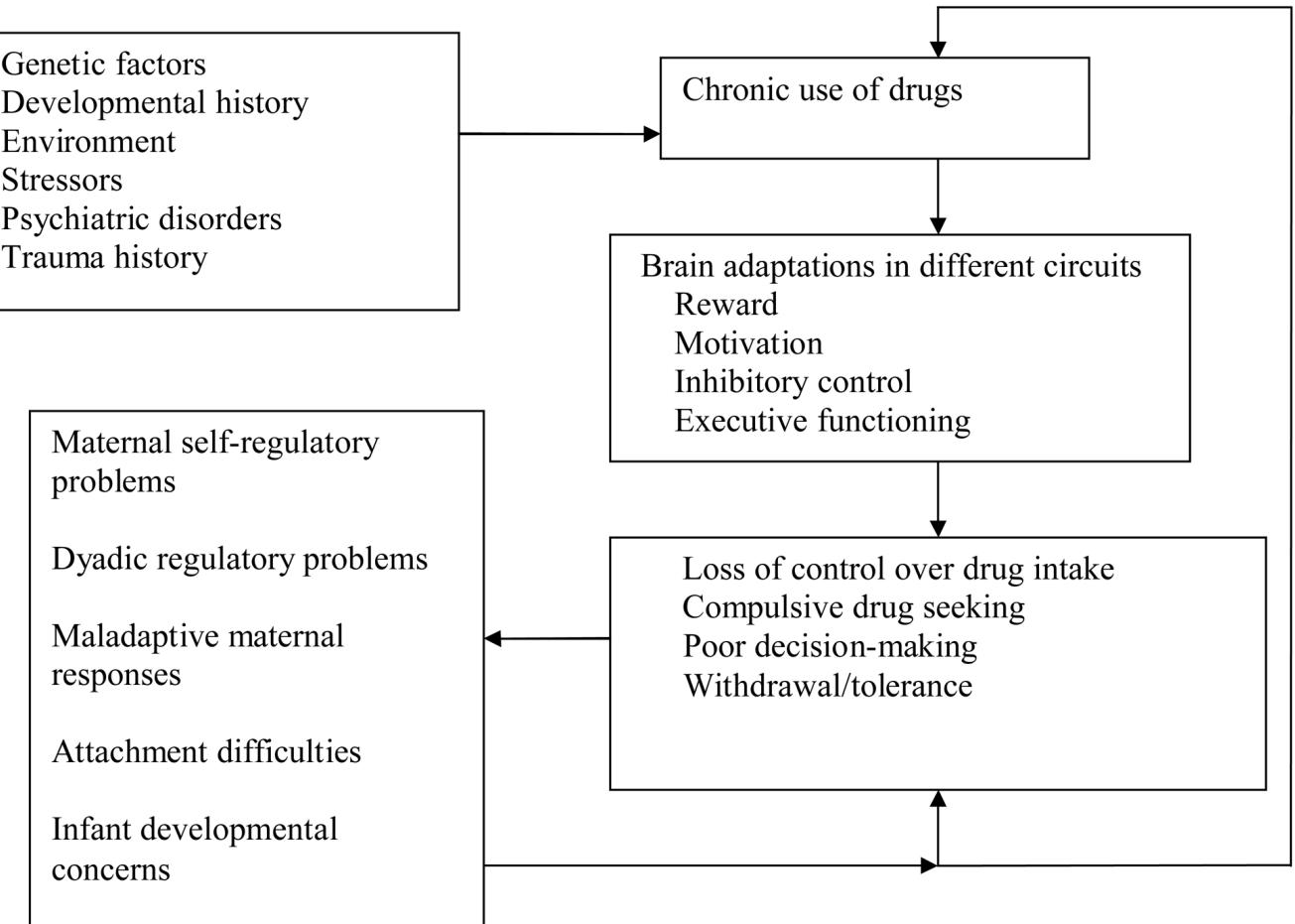
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**Fig 1.**

The neurobiological impact of addiction on maternal functioning and the mother/infant dyad

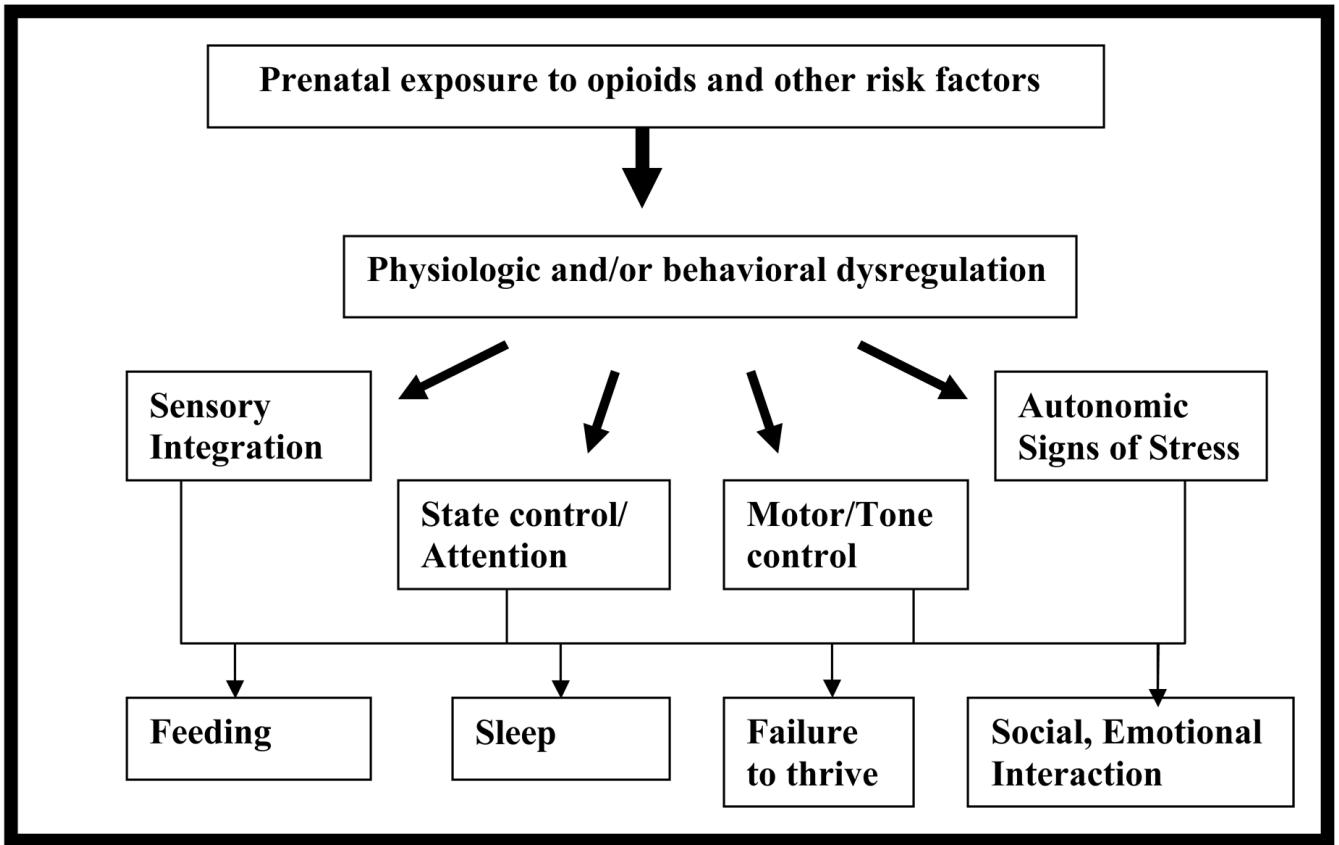


Figure 2.

The neurobehavioral domains and functions of the infant that are affected by NAS

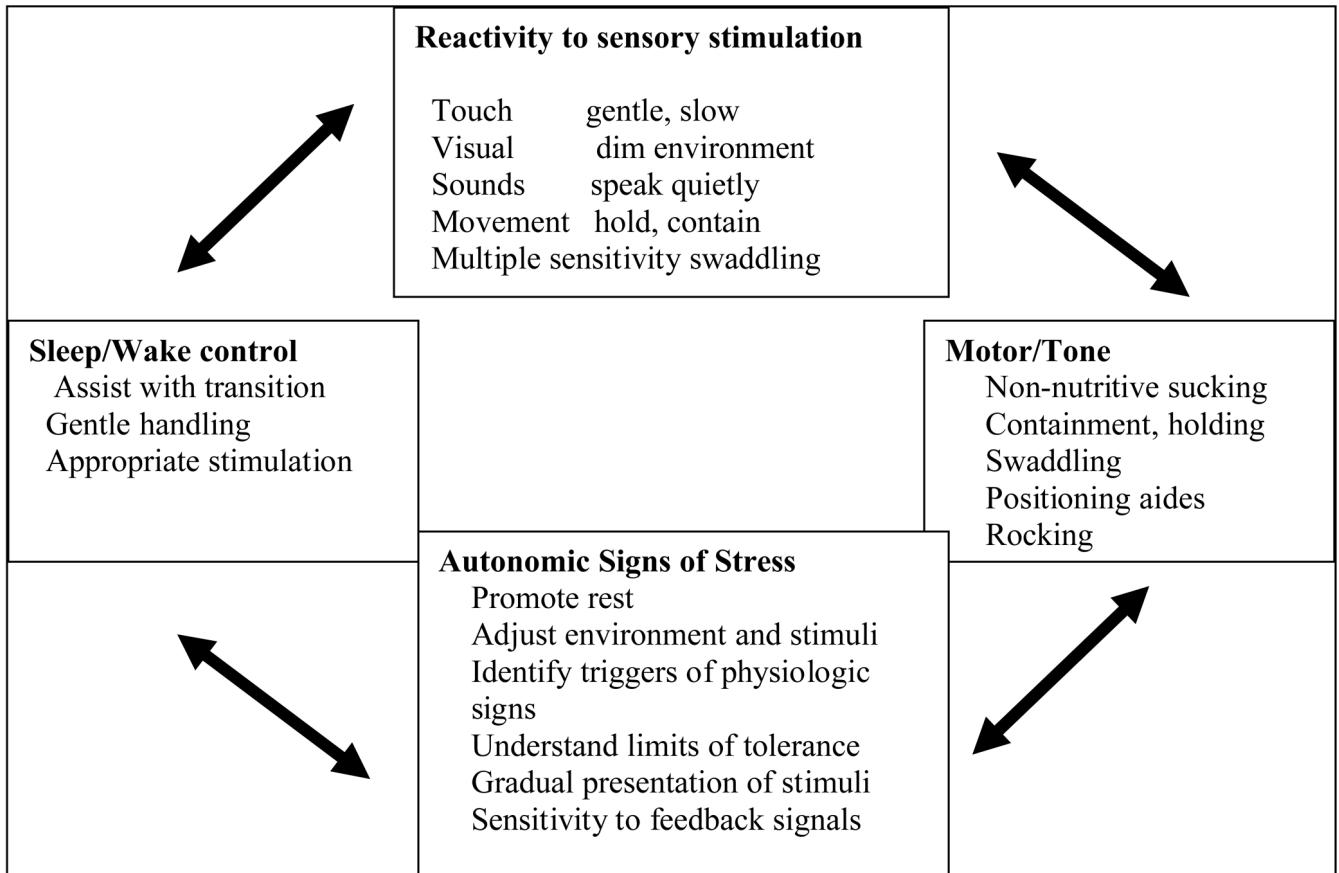


Figure 3.
Non-pharmacologic care by domain for the infant affected by NAS



Figure 4.