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Perinatal Substance Abuse: Personal Triumphs and Tragedies

by
NANCY RUHLE*

Introduction

The problem of perinatal substance abuse is deeply disturbing for the various professionals involved. Pediatricians, obstetricians, neurologists, nurses, social workers, therapists, drug rehabilitation counselors, teachers, ethicists, attorneys, and judges all find themselves, at one time or another, wrestling with the complex issues and ethical dilemmas inherent in the problem. Divergent opinions abound concerning the best way to approach the issue of women who abuse drugs both prenatally and postnatally.

To tackle the problem of perinatal substance abuse without understanding the nature of addiction and without intimate knowledge of the experience of addicts is to invite failure. Throughout the following series of narratives I have attempted to provide a glimpse of the real women and children who are the subjects of so much rhetoric. The stories are incomplete and viewed only from the perspective of one public health nurse, but they help to exemplify the complexity of the problem of perinatal substance abuse.

For those unfamiliar with the role of public health nurses, an explanation is in order. Public health nurses are registered nurses who hold at least bachelor's degrees and certificates in public health nursing. Although some public health nurses working for private agencies provide hands-on care to the sick in their homes, the nurses referred to in this Article are county-employed. Their nursing care in and out of clients' homes focuses on family health and is predominantly psychosocial in nature. Because public health nurses are nursing generalists, their clients run the gamut from tiny premature infants to the elderly. They work

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with these clients in a wide range of community settings that include diverse ethnic groups from a variety of socioeconomic backgrounds. The nurses' responsibilities include family health assessment, coordination of health care, referrals as needed, health education, and prevention of specific diseases or complications. Their health-related services include the areas of communicable disease, tuberculosis, family planning, maternal and child health, child abuse, senior health, and many more.

In the area of maternal and child health the public health nurse functions in a unique role: she is an advocate simultaneously for mother and baby. Ordinarily, this arrangement is both natural and positive. However, in the event of conflicting needs, when the child's welfare is at stake, the child's needs unarguably take precedence over the parent's. This is most noticeably evident in cases involving child neglect or abuse, which often occur when a parent's severe substance addiction has compromised her ability to care for her child. Most of the women in the cases discussed below lost custody of their children, temporarily or permanently.

The following stories illustrate the emotional and sometimes physical trauma experienced by substance abusing mothers and their offspring. The general population is acutely aware that the children of addicts suffer because of prenatal exposure to drugs or parental neglect after birth. What is less well understood is that their mothers are powerless to simply stop using drugs. Even less well known is the fact that, in spite of the harm they inflict, these women love their children very much. These are their stories.

Mary

Mary¹ is an extreme example, but not a rare one, of a substance abusing perinatal client. A recovering addict, she was one of my favorite clients. When I last saw her, Mary was thirty-four years old, but looked forty-four. As a child, she suffered psychological and sexual abuse (a common history among chemically dependent women). She had no memory of her life prior to the age of six. Her four upper front teeth were missing and she suffered chronic back pain, the result of having been hit by cars three times and falling down stairs during periods of inebriation. For eleven years she used a variety of chemical substances, including alcohol, cocaine, and heroin; she also was a chain-smoker. She prostituted to support her habit, and her partners included both males and females. She was in and out of jail. Her two older children were

1. For reasons of confidentiality, all names used are fictitious.

removed from her custody, and in 1990, shortly after using cocaine and heroin, Mary gave birth ten weeks prematurely to a neurologically impaired boy. She was on methadone² at the time, and her baby was treated for neonatal withdrawal syndrome.³

Everyone pays a price for perinatal substance abuse, and no one pays more than the infant who has been exposed throughout pregnancy to one or more drugs. Thomas, Mary's baby, spent the first month of his life in the hospital and the following nine months with a caring foster mother. During this time he had periods of inconsolable crying and frantic sucking, plus tremors of his limbs that lasted until the age of seven months. When I last saw him, Thomas was fifteen months old. He was undersized, his facial features were asymmetrical, his head circumference was below the fifth percentile, and he had greater coordination with the right side of his body than the left. His medical specialist believed Thomas probably would have mild cerebral palsy.

At the age of ten months Thomas was returned to Mary's care. After Thomas' return, Mary demonstrated an observable sensitivity to her child's needs and was eager for any and all information that would increase her knowledge of her child's growth and development and promote her parenting skills. She and Thomas were obviously happy together. Mary's life, however, continued to be complicated by stressors and obligations: frequent medical appointments; therapy twice a week; Alcoholics Anonymous meetings; appointments for drug testing; and finally, an unexpected need to find a new source of housing for herself and Thomas.

Working with a woman in recovery, who is struggling against incredible odds and has managed to turn her life around, is a rewarding experience. During her years of substance abuse and life on the streets Mary attempted to undergo drug treatment several times but relapsed each time. Asked what the turning point was, she replied, "I just got tired of being sick."

I was most encouraged when Mary confided that she had recognized some early signs of relapse in her recovery. She said, "I was feeling really stressed out and I was impatient with Thomas. So I sat down and asked myself what was happening here. Well, I had been missing some AA

2. Methadone hydrochloride is a chemical compound derived from opium. It is used as a heroin withdrawal substitute and for maintenance programs. It should be noted that methadone itself is addictive.

3. In neonatal withdrawal syndrome a newborn baby experiences withdrawal a few days after birth. Symptoms can be varying degrees of tremors, feeding problems, diarrhea, crying, fever, sleep disturbance, and more. In the hospital where Mary's third child was born the treatment of choice to alleviate these symptoms was tincture of opium.

meetings. That's bad. I had missed appointments. That's *really* bad. So I cut back on some things, slowed down, attended more AA meetings, and now it's okay." The future looks promising for Mary. Less so for Thomas; his growth and development have been severely affected by his mother's prenatal drug abuse.

How could this have been prevented? Controversy rages over the dilemma of women's rights versus fetal rights. Mary had no prenatal care. It is unknown whether this was because she feared the consequences of confrontation once she sought medical care or because she was too immersed in her drug activity to care. Comments from some of my other client addicts regarding addicts' attitudes suggest that the latter reason is more likely. Incarceration for drug-related crimes did nothing to arrest Mary's chemical addiction. Voluntary admission to drug treatment programs resulted in relapses. Even if the law had permitted mandatory confinement in a residential drug treatment program once her pregnancy became obvious to others, in all probability the greatest damage to the fetus already would have occurred.

A public health nurse provides services to mother and child simultaneously and is concerned equally for each of them. Advocacy for the child, however, always takes precedence in the case of abuse or neglect. In the preceding narrative, if Mary were to demonstrate any signs of neglect in the care of Thomas, my responsibility clearly would be to favor Thomas' best interest. This dual role sometimes presents the nurse with an ethical dilemma, particularly when the issue of neglect is not clear. This situation is exemplified by the story of another client, Leona.

Leona

Leona was a young single mother of a two year old daughter. During the period when I was her public health nurse, she was living in a neatly furnished single room of a condominium, and her boyfriend was in jail. Leona was struggling to be a "good parent," receptive to my services and interested in all information relating to parenting skills. Eventually, Leona confided that she used PCP on occasion and that she smoked it outside while her daughter slept. I was faced with the decision of whether to ask Leona if she had another person look after the child on these occasions.⁴ If I asked and Leona answered "no," I then was man-

4. It should be noted that not every public health nurse would agree that I had a choice in asking this question. This, in my opinion, is one of the gray areas of legal responsibility, thus contributing to my ethical dilemma.

dated to report this as general neglect,⁵ and the positive relationship with Leona would be undermined. If I chose not to ask the question, and as a consequence the child suffered in the future, I would have to live with the knowledge that I might have prevented it. After much soul searching—this would be my first experience with filing a child abuse report—I decided to ask the question. Leona's answer was "no." She became understandably angry when I informed her of my reporting responsibilities, but she did agree to see me again. On the following visit there was a perceptible shift in mood. Although she remained friendly and open to learning, there was an element of caution that had not existed previously in our relationship. Not long afterward she announced her intention to move, and I was unable to make contact again.

Mary and Leona exemplify the range of illicit drug use. Leona was a casual user of her drug of choice; Mary was a true addict. Although clients may be anywhere along that continuum at the time they receive public health nursing service, all of them share one attribute: in the initial stages they are in denial. Without a doubt, the most difficult sort of substance abusing client for any public health nurse is one in denial. The difficulty of dealing productively with patient denial is exemplified by the story of Tanya.

Tanya

Tanya was twenty-seven years old and the single mother of three, the oldest of the three having remained with his father, when she was referred by a juvenile probation officer to public health nursing. Tanya's newborn, Aaron, was born "tox positive" to methamphetamine.⁶ His fourteen month-old sibling, Kathy, had also tested positive for the same drug at birth.

On the first home visit Tanya greeted me enthusiastically. She was a tall thin woman with a loud gravelly voice, abrupt in her movements and somewhat rough in the handling of her children. In spite of her lack of physical gentleness, Tanya displayed affection and appeared to provide adequate care for Aaron and Kathy. She freely admitted that she had used methamphetamine by every possible method for an eight year period, but she said that she had been "clean" since Kathy's birth. She claimed that Aaron's positive tox screen was due to her prenatal use of a cough medication (a fact refuted by a laboratory technician familiar with

5. CAL. PENAL CODE § 11165.2 (West Supp. 1992) (child abuse reporting law defining general neglect).

6. A urine toxicology screen had been performed, which showed that Aaron had the metabolite for methamphetamine in his system at birth.

the record). The baby displayed some slight tremors and eventually some increased muscle tone in the extremities, which resolved itself when he was approximately seven months old.⁷ When I pointed out Aaron's substance related problems, however, Tanya consistently denied that her baby had any problems.

Initially, Tanya lived with her mother and stepfather in a crowded apartment where everyone smoked heavily—undoubtedly a major precipitating factor in Aaron's subsequent upper respiratory infections and asthma. When Aaron was approximately four months old, Tanya married a man (not the children's father) who was in prison, and shortly thereafter she moved into her mother-in-law's house in another city. She told me her parents were alcoholics, and because of the nonnurturing family environment, her social worker agreed with the move. I kept the case even though Tanya moved "out of district" (outside the geographical boundaries of my district office) and continued to follow the family through three more moves, all of them out of district. Through this continuity of care, I was better able to accurately assess changes in Aaron's growth and development and in his mother's attention to parenting.

When Aaron was approximately five months old, the social worker expressed his belief that Tanya would progress and eventually would no longer be under the supervision of the Social Services Agency. I was not so optimistic, being aware that Tanya did not follow through on suggestions and that the care of her children was marginal. The social worker required periodic urine tests from Tanya but never demanded that she enroll in a drug rehabilitation program. When a test was positive, Tanya told me but claimed it was a false reading. At the age of nine months Aaron's height and weight began to fall below his growth curve, and I notified Social Services. Shortly thereafter, Tanya moved again, and within a brief period of time both children were removed from her custody. I never learned the precise reason; however, I assume that the children's removal was due to general neglect. Kathy was placed in a foster home. Aaron was placed with an aunt.

As of the date of this publication I continue to provide services to Aaron, monitoring his progress and helping the aunt with parenting issues. Aaron is almost two-and-a-half years old. He is of average height, below average weight, and has a head circumference at the tenth percentile on the growth chart.⁸ A carrot haired kid with protruding ears and a

7. This is an indication of central nervous system involvement.

8. Although a small head circumference is sometimes correlated with diminished intellectual capacity, Aaron's small head may be entirely genetic in etiology. His aunt has informed me that Aaron's father's head is small.

narrow chin, Aaron is active, inquisitive, happy, and developing within normal limits for a child his age. His mother is in jail on charges unknown to me, and his aunt has obtained permanent custody.

Usually, family reunification is the goal of courts, but at times this is not a preferred option. It has been interesting for me to observe the change in Aaron's development once his care was entrusted to the nurturing aunt. His personality has literally blossomed, and he is a joy to watch. Of course, not all children blossom when removed from their parents and placed in a foster home. This is a traumatic experience for children, especially when the foster parents are strangers rather than relatives, and when there is a series of placements.

My relationship with Tanya could hardly be described as productive. Despite that fact, Tanya accepted me, and I was anxious to encourage the growth and development of Aaron. Tanya heard what I said and responded, but she was unable to listen, and there is a difference—one commonly observed by nurses working with substance abusing clients. A client who truly pays attention will make appropriate changes in her parenting, or at least will relate an attempt to do so. Clients in the throes of chemical dependency, however, do not follow through on a nurse's suggestions.

Stella

Working with a client such as Tanya can be frustrating, but even worse is the situation where a client's denial results in tragedy. Such is the story of Stella. She is a thirty year-old, obese, plain-looking woman with a twelve year-old daughter, Karen, who is in the custody of Stella's mother. Stella has been an addict for eight years. For six years she used PCP, then switched to crack. Because of her history of substance abuse, the clinic she attended referred her to public health nursing when she first sought prenatal care. Eventually, Stella was diagnosed with gestational diabetes, and she received prenatal care in a high risk clinic.⁹ I first met her when she was eight months pregnant.

At that time Stella claimed she had been drug free since she discovered the pregnancy. Believing that prior surgeries had left her unable to conceive, she was astonished to find herself pregnant and desperately wanted this baby. Karen also was enthused, and she and her mother found themselves developing a closer relationship. Stella had moved away from the area where her drug-involved friends lived, and although

9. A high risk clinic is that part of an obstetrical clinic which provides services exclusively to women at risk for complications in their pregnancies.

she gave them her phone number and kept in touch, she did not allow them to know her address. She learned to give herself insulin, modified her diet, and kept her numerous appointments at the high risk clinic. Unfortunately, she refused to enroll in a drug treatment program, telling me that she was a strong willed person who could do it on her own if she wanted.

Stella spoke freely with me and tearfully described her family relationships. Although familial interactions had greatly improved, she nonetheless continued to live with personal pain. The baby within her, judged by scan to be a girl, was eagerly anticipated by all concerned. During the last prenatal home visit Stella promised to call me after the next week's appointment at the clinic. She never called. Later I called her apartment and was informed by Stella's boyfriend that her baby was dead *in utero* and at that moment was being delivered at the hospital.

The following day I was able to speak with Stella by telephone. Stella was in anguish over the death of her daughter, and she sobbed through her story. Although Stella was unaware of it, I was crying too. Her membranes had ruptured prematurely, and fetal movement had ceased. Stella said she had sensed the baby was dead but was so desperate to believe otherwise that, when asked, she told her physician that she felt the baby move. On having her child's death confirmed by ultrasound, she became hysterical. Not wanting to induce labor at that point, her physician allowed her to go home with her promise that she would return later in the day. Still denying that her baby was dead, she could not be persuaded by her family to return until the following day. After a long and difficult labor the baby was delivered, and Stella, her mother, and Karen each held the dead infant, sharing their love and their grief. When Stella finished telling her story, I arranged to make a home visit after her discharge from the hospital.

One day later a hospital social worker telephoned me with more bad news: Stella had used cocaine prior to the rupture of the membranes. Although the doctors discussed with Stella the known correlation of cocaine use with premature rupture of the membranes, she continued to deny that the cocaine could have caused her baby's death. While still in the hospital, she told the social worker that her sister had used cocaine during all her pregnancies "with no problem," and therefore her "one time" use could not be the cause.

Stella did not keep the appointment with me, and all of my further attempts to see her have failed. I have left the door open for contact, and I can only hope that Stella eventually will seek me out. In the meantime, this distraught woman stands at a major crossroads in her life. She can

pursue the referral to a drug rehabilitation program, or she can slide into an ever deepening abyss of addiction.

Louise

At the other extreme is Louise: a success story, the likes of which nurses and other professionals eagerly embrace. Even an occasional triumph over drug addiction helps compensate for the numerous relapses. Incarceration failed to influence the addictions of Mary and Tanya; for Louise it was the turning point in her life. The difference lay in Louise's choosing to participate in a voluntary drug rehabilitation program offered by the jail. Louise has told me that only the experience of being forcibly removed from her home environment motivated her to begin the road to recovery.

Tall, slim, and well-groomed, Louise is the mother of three daughters several years apart in age. Three of her relatives are alcoholics, and Louise herself began substance abuse with alcohol, eventually switching to cocaine. Her youngest daughter, Rebecca, was exposed to cocaine during the first two months of pregnancy. Like so many other substance exposed infants, she exhibited some early tremors followed by an increase in muscle tone, which was diminished a few months later. As of this writing, Rebecca is three years old, and her growth and development appear to be normal. Many more longitudinal studies must be completed, however, before we can achieve a consensus as to the proper long-term prognosis for cocaine exposed offspring.

During the first home visit with me, at which time she had been drug free for seven months, Louise was able to express her feelings about her addiction; she described the physical sensation that overcame her even when she simply talked about cocaine. She commented on the power of cocaine, stating that, when she was using it, she did not care what happened to her children. The one and only thing that mattered in her life was the drug. I was eager to learn more about the physical and emotional sensations experienced by a cocaine addict, but it was too distressing to Louise to describe her feelings in detail. She was determined to recover from her addiction and had broken off her engagement to marry Rebecca's father because he was unwilling to undergo drug rehabilitation himself. With the support of her social worker, counselor, and nurse, Louise has managed to continue her recovery to this date. She has moved to a different area of the county, gotten a part-time job, and enrolled in a community college, hoping eventually to move on to a baccalaureate program. She says she plans to invite me to her graduation.

Conclusion

The preceding stories constitute only a small portion of one public health nurse's experiences with substance abusing clients. Each client is unique, but the details of the stories are all too similar: dysfunctional family relationships; histories of sexual, physical, and verbal abuse; violence; low self-esteem; and utter despair. At one time or another, each professional who comes into contact with these women experiences feelings of frustration and inadequacy, wondering if within his or her lifetime there will be a resolution to this major societal problem.

To achieve such a resolution we must intervene more effectively early in the lives of youngsters at risk for substance abuse. We must provide an adequate number of the kind of residential treatment programs so sorely needed by pregnant and parenting women. We must become more skilled at breaking the cycle of abuse. We must do so, not only for the sake of future Thomases and Rebeccas, but for the sake of us all.