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Identifying Gaps in Transitional Care for Adolescent Parents and Their Infants Leaving the NICU: A Needs Assessment

Abstract

Parents of infants admitted to the Neonatal Intensive Care Unit (NICU) are more likely to experience posttraumatic stress, anxiety, feelings of hopelessness, difficulties caring for or bonding with their infants, and financial concerns than parents who deliver full-term, healthy newborns (Ionio et al., 2016). Some NICU admissions may last several months before the premature and/or critically ill infant is stable enough for discharge, and other times the likelihood of discharge is uncertain. Arguably, teen parents with NICU infants are confronted with even more stressors throughout their newborn's hospitalization and post-discharge when they settle into their role as a new parent. Although the health and mental health outcomes of adult NICU parents are well documented in the literature, less research has investigated the unique challenges of supporting young parents and their NICU infants, as adolescent parents tend to be absent from the majority of empirical studies. Further, and perhaps more importantly, few qualitative research studies include interviews with NICU providers with insight into the treatment needs of teen parents and what may be lacking. This study conducted needs assessments with various NICU medical and mental health providers in Denver, Colorado to determine what additional resources or services may be useful for teen parents and their babies transitioning home from the hospital. A list of identified resources in Colorado for teen parents in the NICU is provided at the end of this paper (see Appendix B).

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THEIR INFANTS LEAVING THE NICU

IDENTIFYING GAPS IN TRANSITIONAL CARE FOR ADOLESCENT PARENTS AND
THEIR INFANTS LEAVING THE NICU:
A NEEDS ASSESSMENT

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Abstract

Parents of infants admitted to the Neonatal Intensive Care Unit (NICU) are more likely to experience posttraumatic stress, anxiety, feelings of hopelessness, difficulties caring for or bonding with their infants, and financial concerns than parents who deliver full-term, healthy newborns (Ionio et al., 2016). Some NICU admissions may last several months before the premature and/or critically ill infant is stable enough for discharge, and other times the likelihood of discharge is uncertain. Arguably, teen parents with NICU infants are confronted with even more stressors throughout their newborn's hospitalization and post-discharge when they settle into their role as a new parent. Although the health and mental health outcomes of adult NICU parents are well documented in the literature, less research has investigated the unique challenges of supporting young parents and their NICU infants, as adolescent parents tend to be absent from the majority of empirical studies. Further, and perhaps more importantly, few qualitative research studies include interviews with NICU providers with insight into the treatment needs of teen parents and what may be lacking. This study conducted needs assessments with various NICU medical and mental health providers in Denver, Colorado to determine what additional resources or services may be useful for teen parents and their babies transitioning home from the hospital. A list of identified resources in Colorado for teen parents in the NICU is provided at the end of this paper (*see Appendix B*).

Keywords: adolescent pregnancy, teen parents, NICU, health outcomes

Context of the Study

There is extensive scientific evidence that links risk factors, including delinquency, substance use, and low educational attainment, to early parenthood (Spicer et al., 2014). These co-occurring behaviors and risk factors are associated with an increased likelihood of contracting sexually transmitted infections (STIs), lower likelihood of seeking adequate prenatal care, and other problematic behaviors, all of which impact an adolescent's reproductive health. Consequently, adolescent mothers are at increased risk for complications during delivery and following birth that result in NICU admissions.

Little research exists regarding the mental health treatment and standard of care for adolescent mothers with infants admitted to the NICU, as subjects under the age of 18 are often excluded from empirical studies. Further, literature involving adolescent pregnancy outcomes is abundant, while studies that specifically target young parents with medically complex, fragile infants in the NICU are less frequent. One such systematic review was conducted in 2014, although additional reviews and empirical studies since that time are scarce (Rosenstock & van Manen, 2014). This systematic review, which retained 22 articles meeting inclusion criteria between 1990 and 2014, identified methodological inconsistencies, such as the defined age of adolescence, sampling strategies, and exclusion criteria, that hinder the generalizability and validity of inferences of such research. This review also emphasized what minimal attention is given to sociocultural factors (i.e., living arrangements, family support, socioeconomic status), which hugely impact adolescent parenting in the NICU. To date, few (if any) studies include interviews with NICU clinicians working with this population. The purpose of this investigation is to explore mental health providers' experiences working with young mothers in the NICU and to improve understanding of how to most effectively support them along their journeys.

Literature Review

Prior to this investigation, a careful review of existing evidence in the research literature regarding adolescent pregnancy risk factors/outcomes, as well as standards of care for NICU families, was conducted. Teen parents' experiences in the NICU, including parent-staff communication, parental needs, and adolescent-specific programs, were given central consideration.

The adolescent phase of development is often characterized by impulsive, risk-taking behaviors, which hold potential for detrimental health outcomes. The study of adolescent risk-taking behaviors gained prominence in the 1980s, when researchers began recognizing and investigating the developmental trajectory of such behaviors (Igra & Irwin, 1996). In this context, risk-taking behaviors are considered volitional behaviors that yield uncertain outcomes, although with the possibility of an identifiable negative health outcome. Such behaviors, including substance use, risky sexual behaviors (i.e., sexual activity in the absence of contraception, multiple sexual partners), reckless driving, homicidal or suicidal behaviors, eating disorders, and other behavioral misconduct, are shown to increase during adolescence (Igra & Irwin, 1996).

The adolescent brain experiences many biological and physiological changes that, in turn, have a variety of effects on behavior. These changes in adolescence are specific to regions in the brain that are most important for modulating behavioral and affective responses to risks and rewards (National Institutes of Health [NIH], 2011). The prefrontal cortex, which undergoes significant change during adolescence, is the site of control functions that help modulate sensitivity to rewards and can inhibit impulsive or emotional responses based on rational decision-making capabilities. While the prefrontal cortex develops slowly and gradually, the

limbic system, known to house emotionally laden memories and functions, follows a quicker developmental trajectory. This differential development of the limbic system relative to prefrontal control regions leads to an imbalance in brain systems, which favors incentive- or emotion-driven behaviors over rational decision-making abilities (NIH, 2011). Conceptually linked to this biological theory of adolescent risk-taking behaviors is unplanned pregnancy; however, psychosocial factors also largely play a role.

The World Health Organization (WHO, 2019) defines adolescent pregnancy as any pregnancy to girls between the ages of ten and 19, with age being identified as the mother's age at the time of childbirth. In 2014, it was estimated that approximately 11% of births worldwide were attributed to adolescents aged 15 to 19 (Ganchimeg et al., 2014). While prevalence rates of adolescent pregnancies vary drastically across countries, it is believed that every fifth child is born to a teenage mother, accounting for approximately 13 million births each year worldwide (Yasmin et al., 2014). In the United States specifically, despite a trend in decline, teenage childbearing rates are higher than any other comparably developed nation (Bennett et al., 2013). This statistic reflects the important role of assessment of health care and mental health care needs of teen parents among pediatric practitioners.

Across both developed and developing regions, literature unanimously concludes that adolescent pregnancies most commonly occur in marginalized communities and depend on a number of societal and personal factors. For the large majority, high rates occur within the context of poverty, inaccessible or inadequate health care due to lower socioeconomic status or living in rural areas, lack of educational or employment opportunities, and environmental and/or familial influence (e.g., family history of teenage pregnancies, being born to an adolescent mother). Racial disparities exist, as evidenced by a large body of literature. In 2017, the U.S.

birth rates of Hispanic teens (2.89%) and non-Hispanic African American teens (2.75%) were more than twice the rate for non-Hispanic White teens (1.32%) (Taylor, 2017). Today, the birth rate of American Indian/Alaska Native teens (3.29%) remains the highest (CDC, 2020), a subset of the population notorious for adverse childhood experiences and mental health treatment needs. Academic functioning and educational attainment are also known correlates of adolescent pregnancy. In examining the correlation between pre-teen literacy and teenage pregnancy, Bennett et al. (2013) found that lower-than-average reading skills were associated with an increased risk of teenage childbearing, particularly among African American and Hispanic/Latina girls.

One study examining the utility of the Social Vulnerability Index (SVI), a measure originally developed to assess emergency preparedness, found that higher social vulnerability, related to factors such as socioeconomic status, household composition, minority and/or language status, was positively associated with teen pregnancy (Yee et al., 2019). Similar to the Social Vulnerability Index (SVI), multiple studies of Adverse Childhood Experiences (ACEs) demonstrate strong correlations between childhood abuse and neglect and poorer health, vocational, and relationship outcomes (Hillis et al., 2004; Smith et al., 2016; Magill & Wilcox, 2007). One empirical study examined the relationship between childhood exposure to physical abuse, sexual abuse, and/or domestic violence and early parenthood among teen males. Anda et al. (2001) analyzed data from 4,127 men who provided information regarding reproductive history and traumatic experiences in childhood as measured by the ACEs. They discovered that 43.3% of men involved in an adolescent pregnancy reported experiencing at least one of three types of adverse experiences, including physical abuse, sexual abuse, and/or domestic violence; 10.1% endorsed two of three adverse experiences; and 2.3% reported histories of physical abuse,

sexual abuse, and domestic violence. Overall, the study concluded that males with a history of childhood physical abuse, sexual abuse, and witnessing domestic violence were more likely to become teen fathers (Anda et al., 2001). Another ACEs study indicated that adverse childhood experiences are correlated with increased substance use, increased number of sexual partners, and earlier age of first intercourse (Cunningham et al., 1994; Nelson et al., 1995; Hernandez et al., 1993). Further research investigating adverse childhood experiences demonstrates correlations with poorer health and mental health outcomes, which extend from the family of origin to the wellbeing of future generations of children. However, an important critique of the ACE methodology to consider is the fallibility of self-reported maltreatment in childhood and the construction of narratives involving abuse, neglect, and/or misfortune. Recalling events in childhood cannot be relied upon for literal accuracy, making these conclusions speculative and presumptive based on plausible correlations (Karson, 2018). Further, longitudinal research actually suggests children are resilient and able to overcome adverse events (Landes et al., 2014). Thus, while ACEs can be informative for individuals and providers to understand or explain outcomes in adolescence or adulthood, other measures, such as the SVI, related to other variables (e.g., socioeconomic status) may eliminate the persuasion of remote recall and may prove more accurate when determining correlations between historical and current circumstances.

Homeless and foster care youth constitute a large subset of adolescent pregnancies. Studies assert that high rates of teen pregnancies among this population are related to an increased risk of exposure to abuse or domestic violence, a lack of stable housing, disrupted placements, feelings of abandonment, and the potential absence of consistent, stable relationships with caregivers or mentors (Thompson et al., 2008; Boonstra, 2011; Manlove et al., 2011). However, economic hardship is often understood as the best predictor of foster care involvement

and poverty is perhaps the most common, underlying risk factor for child maltreatment (Dworsky et al., 2007). These risk factors result in a multifaceted view and understanding of teen pregnancies and the complications they can pose. The Midwest Evaluation of the Adult Functioning of Former Foster Youth, a prospective study assessing health outcomes of foster care youth, found that by age 19, girls with a history of foster care involvement were two-and-a-half times more likely than other girls nationwide to become pregnant (48% versus 20%) and nearly three times more likely to bear a child (32% versus 12%) (Courtney et al., 2007). Similar findings were true of adolescent males' involvement in pregnancies: nearly one half (49%) of 21-year-old men who had aged out of the foster care system reported to have impregnated someone, compared to 19% of young men nationwide (Courtney et al., 2007). Because of this, continued vigilance of pediatricians, social workers, teachers, and other providers involved in children's care to identify both boys and girls exposed to abuse or domestic violence may be a crucial component of teen pregnancy prevention, as well as interventions targeting youth in foster care or at risk for foster care placement. It further reflects the importance of identifying supportive resources and services for postnatal teen mothers.

Adverse Outcomes

Adolescent pregnancy remains a global public health problem due to its association with adverse maternal and fetal health outcomes. Literature suggests these at-risk and high-risk pregnancies are associated with preterm labor, anemia, Hypertensive Disorders of Pregnancy (HDP), Urinary Tract Infections (UTIs), Sexually Transmitted Infections (STIs), HIV, malaria, high rates of Cesarean Sections due to fetal distress, and mental illness (Dutta & Joshi, 2013). Other studies link higher rates of unplanned pregnancies and lack of prenatal care among adolescent girls to higher rates of neonatal illnesses and intensive care hospitalization (Boss et

al., 2010; Banerjee et al., 2009). Dutta & Joshi (2013) evaluated the maternal and fetal outcomes of adolescent and adult mothers, determining that younger mothers experienced more complications during pregnancy and post-birth. It was found that adolescent mothers were significantly more likely to develop medical conditions, such as anemia, hypertension, oligohydroamnios, and hypothyroidism, than adult mothers. One study examining differences in perinatal outcomes among younger adolescents (<15 years of age), older adolescents (between ages 16 and 19), and young adults (between ages 20 and 25) found higher risks for preterm delivery and maternal anemia among the younger and older adolescent cohorts (Kawakita et al., 2016). Compared to 5% of adult subjects, 25% of teen mothers had preterm births, resulting in a higher number of low birth weight infants and NICU admissions (Dutta & Joshi, 2013). These studies are corroborated by research concluding that adolescent mothers typically have an increased risk of prolonged length of stay after delivery (Torvie et al., 2015). Given these findings, which implicate more difficult perinatal courses than for older mothers, close follow-up, mental health support, and education are highly important for young mothers.

Regarding mental health, research suggests prevalence rates of postpartum depression reach 15% among adult women and nearly 30% in teen mothers (Postpartum Support International [PSI], 2020). Among the contributing factors to postpartum depression are previously diagnosed psychiatric illness, poor marital relationship, stressful or traumatic life events, negative attitude towards pregnancy, and a lack of social support (Norhayati et al., 2015). Given that adolescent mothers are typically more susceptible to such risk factors, it is understandable that there are higher rates of postpartum depressive symptoms in teen mothers, and some research suggests symptoms may develop in up to 54% of young mothers (Dinwiddie et al., 2016; Sangsawang et al., 2019). It is further theorized that given the high rates of adverse

childhood experiences reported among teen parents, complications during delivery or following birth may even further exacerbate predispositions for mental health symptoms related to traumatic childhood events. Consequently, teen parents are at high risk for distress during and after pregnancy due to the compounding impact of contributing risk factors and related increased likelihood of infant NICU involvement.

Potentially negative parenting and educational outcomes are also documented for teen parents in the literature. For example, between 1998 and 2006 in Illinois, about one in five teen mothers in foster care were investigated for child abuse and neglect of their own children, which strongly implicates intergenerational pattern of abuse and neglect (Courtney et al., 2005). Perper et al. (2010) determined that teen mothers were significantly less likely to earn a high school diploma than other adolescent females by the age of 22, whereby only 51% of teen mothers completed high school compared to 89% of school-aged girls who had not given birth as an adolescent.

Impact on Infant-Caregiver Attachment

The health complications often treated in the NICU, including poorly regulated body temperature, respiratory distress, feeding challenges, reflux, and dangerous infections, make caregiving a daunting task. Parents of NICU babies are more likely to experience posttraumatic stress, anxiety, feelings of hopelessness, difficulties caring for or bonding with their infants, and sleep disruptions than parents who deliver full-term, healthy newborns (Ionio et al., 2016).

One empirical study utilizing the Parental Stressor Scale: NICU (PSS:NICU) cited mother-baby relationships, the appearance and behavior of the infants, and the NICU environment as the most stressful aspects of hospitalization among the 46 adolescent mothers who completed the questionnaire (Bell, 1997). However, conflicting data obtained from various

studies using the PSS:NICU exists due to variations in timing of administration, demographic makeup of the study, and sociocultural contexts. In 1972, researchers examined the effects of mother-infant separation on maternal attachment behavior, or the degree to which a mother is attentive to and maintains physical contact with her infant. Leifer et al. (1972) found that mothers with limited contact for longer periods of time resulted in a more negative impact on both the mother and baby. The study cited a lack of physical contact and fewer NICU visits as negatively impacting the infant's overall health status, the mother's postpartum recovery, and her commitment to mothering. Leifer et al. (1972) also observed higher levels of stress, feelings of hopelessness, and difficulty adjusting to their infant's condition or prognosis in mothers with limited contact, such as those who could not visit their baby immediately following birth or those with intubated infants in isolettes for longer periods of time. Lastly, it was concluded that mothers who were separated from their babies had strained relationships with their medical providers, had poorer communication with the treatment team, and expressed an overall distaste for the NICU environment (Leifer et al., 1972). Later research provides more substantiating evidence to prove the detrimental effects of NICU hospitalizations on the mother and infant. Pennestri et al. (2015) shared that prolonged periods of maternal separation in early life increased the mother's neuroendocrine response to stress, and ultimately their vulnerability to stress-related illnesses. Results from this study also suggested NICU infants are more likely to develop disorganized attachment styles than full-term, healthy infants as a result of potentially prolonged separation from their primary caregivers. What is drawn from these studies is that disrupted attachment may be the culmination of infant vulnerability, the infant's lack of responsiveness to the mother's maternal behaviors, difficulty caring for a NICU newborn, and the psychological effects of a premature birth. Thus, literature unanimously emphasizes the

importance of facilitating closeness between mothers and infants in order to enhance maternal caretaking and attachment behavior.

Questions arise regarding the bonding experiences between teen parents and their NICU babies. Similar to adult parents, teens have concurrent demands such as schooling, job responsibilities, and socialization, although general statistics of the adolescent's frequency of visitation or presence in the NICU (and thus, ability to bond with their infant) remains unknown. In the systematic review completed by Rosenstock and van Manen (2014), findings of several studies examining adolescent parents' behaviors towards their infants demonstrate less affectionate behaviors among teen fathers compared to older fathers. Further, three cited studies indicated a positive correlation between maternal age and intention to breast feed, where older mothers were more likely to breast feed their infants and therefore experience the intimate bonding opportunity breast feeding offers (Harrison & Woods, 1991; Sommer et al., 1993; Christopher et al., 2000).

Parental psychopathology interferes with parents' responsiveness to a child's needs, decreases tolerance to negative affect, and overall inhibits parents' ability to cope with personal stressors (Davies, 2011). Hoffman et al. (2006) suggested depressed mothers lack crucial parental attributes, including warmth, sensitivity, and the ability to provide a structured environment that encourages curiosity. Furthermore, it is a caregiver's responsibility to help the children learn to self-regulate and make meaning of their internal and external experiences. By modeling appropriate emotional expression, behavioral responses to certain circumstances, and openly communicating their needs, children internalize these adaptive strategies and functions into their later years. This ability to scaffold, an essential aspect of parent-child interaction, is impaired in mothers with depression (Hoffman et al., 2006). Infants are particularly sensitive to

parents' ways of regulating anxiety and tend to imitate or internalize these behavioral responses for their own evolving self-regulation. A history of trauma, in addition to daily stressors associated with limited social support or financial resources, has compounding effects on parental perception of competence and feelings of helplessness (Davies, 2011). For teens with infants in critical condition, maintaining composure, managing their stress levels, bonding with their babies, and making rational, intentional treatment decisions can be extremely difficult given the stressors associated with a NICU hospitalization. As is natural in human development, adolescents are generally less cognitively equipped to navigate and cope with intense emotions (Rosenstock & van Manen, 2014). Biological, emotional, and hormonal responses to a traumatic birth can therefore interfere with a teenager's ability to communicate with their medical providers or adequately care for their infant. This makes mental health support extremely important as teens prepare to transition home from the hospital. Teen parents, in addition to experiencing potentially traumatic births or adverse postnatal health outcomes, constitute a population that is already at-risk due to statistically higher rates of mental health issues.

Relationship with Health Care Providers

A family-centered approach is the standard of care among NICU facilities in the United States. Family-centered care identifies the family as the child's primary source of strength and support, therefore promoting a collaborative relationship between the family and medical providers when making important treatment decisions. Shared decision-making is challenging for both the treatment team and families, given the need to integrate complex medical information, prognostic uncertainty, time pressures, and intense emotions (Boss et al., 2010). This approach integrates respect, choice, information, flexibility, empowerment, and support into

all levels of service delivery and care, and hinges on the strength of the patient-provider relationship.

The patient-provider relationship can hugely influence parents' transitions into the home environment and perceptions of their NICU experiences long after discharge. Relationships among staff and parents may be hindered or positively impacted depending on the providers' acknowledgement and support of families' psychosocial needs (Hall et al., 2015). In understanding the emotional impact of this often unexpected, life-changing event, medical providers may utilize methods of screening for perinatal mood and anxiety disorders, normalize parents' common emotional responses, and provide psychoeducation on mental health symptoms following birth (Hall et al., 2015). It is equally as crucial for providers to be aware of cultural differences that may impact patient-provider communication or sense of trust. Parents who are younger, less educated, non-English speaking, or of lower socioeconomic status are more likely to have lower health literacy skills (Dutta & Joshi, 2013). Therefore, medical staff must be flexible and conscientious when delivering important information in an understandable way. One study investigated the use of short message service (SMS) technology and its impact on family-provider relationships. Results from this study indicated this user-friendly technology was an effective method of information delivery to families and enhanced communication, parents' sense of provider availability, parents' comfort approaching their physicians, and improved parental satisfaction with what medical information was provided to them (Globus et al., 2016).

The impact of maternal age on parent-staff communication and relationships has been considered in multiple empirical studies. Boss et al. (2010) assessed adolescent mothers' understandings of their infant's medical illnesses and perceptions of interactions with NICU staff. Results suggested that teenage mothers could identify their infant's primary medical

diagnosis and course of treatment, but often underestimated the illness severity. In conducting interviews with and administering open-ended surveys to teenage mothers, researchers determined that many conversations between the parents and providers focused on daily updates as opposed to the infant's overall condition or management plans. It was further reported that many teen parents were reluctant to ask for clarification of medical terminology and asked fewer questions than older parents (Boss et al., 2010). Additional literature cites that this lack of communication may be partially attributed to adolescents' desire to appear more knowledgeable, competent, and mature, as a result of potential insecurities regarding how medical providers perceive them as parents (Rosengard et al., 2006; Davis et al., 2001). Robinson (1992) posits that adolescents may lack the foresight pertaining to parenting demands if they are first-time parents and may struggle to recognize the salience of institutional support. He further cites that their desire to assert independence, their cognitive and emotional development, or sense of distrust may preclude help-seeking behaviors. Similarly, another study administered the Neonatal Intensive Care Unit Family Needs Inventory and discovered that younger parents rated the need for support and comfort, as well as overall service needs, as less important than their older counterparts (Mundy, 2010). Moreover, older parents rated the needs for church-based support, guidance regarding the infant's care plan, support from other families, and educational classes related to premature infant care as more important (Mundy, 2010).

Several teen mom support programs in NICUs across the country have been implemented and yielded promising results. Walsh and Goser (2013) developed a six-week Teen Parent Support program consisting of weekly-facilitated sessions covering topics related to self-care, bedside skills, staff communication, and discharge planning. Preliminary results indicated enrolled parents reported feeling more competent in caring for their babies and more supported

by NICU staff. One appealing aspect of the program was the inclusion of a teen graduate from the NICU, who could motivate and encourage teen parents to continue their education (Walsh & Goser, 2013). Several empirical studies have examined the efficacy of the Creating Opportunity for Parent Empowerment (COPE) program, which provides audiotaped and written material regarding information on premature infants, ways of participating in their child's care, and implementation activities (Melnik et al., 2004; Oswalt et al., 2013). While this program is not specific to adolescent parents, several researchers found that participation in the program reduced anxiety in young mothers (Oswalt et al., 2013).

Methodology

The current study used a qualitative method to conduct this needs assessment. A data collections tool in the form of a semi-structured interview was developed to target certain topics related to medical and mental health providers' experiences of working with adolescent parents in the NICU. A thematic analysis was conducted to determine the presence of themes and meaningful concepts was used as the primary method of analyzing the collected data in the form of interview scripts. Patterns were identified through a process of data familiarization, data coding, theme development through inductive reasoning, and theme revision. Out of nine licensed mental health providers identified by the University of Denver faculty and through professional networking at local hospitals, five providers practicing in the state of Colorado consented to and participated in this study. Three of these subjects are currently licensed and practicing in local NICUs in the Denver Metro area, while the remaining two previously worked in a NICU and specialize in infant mental health. Participants' NICU experiences span between one-and-a-half to 33 years.

Survey Instrument

A list of 14 closed- and open-ended questions was created and utilized to conduct semi-structured interviews (*see Appendix A*). This semi-structured interview was intended to explore participants' professional roles they have assumed at their institutions; experiences of working with young parents whose infants were admitted to the NICU; to gain understanding of effective treatment and existing treatment protocols; and to identify possible gaps in care for this vulnerable population.

Findings

The roles of participants included in this study varied: licensed psychologists, licensed professional counselors, and registered nurses were interviewed and provided insight across several health care disciplines, offering a richer and broader scope of data to analyze. A majority of participants reported working in other branches of the hospitals, including OB/GYN clinics, Labor and Delivery (L&D) units, a high-risk antepartum program, and a pediatric intensive care unit (PICU), as well as private practice clinics specializing in infant mental health and perinatal mood disorders. Similar to an integrated behavioral health model, most mental health providers described their roles as NICU consultants where they receive direct referrals from medical providers on a case-by-case basis. Further, one participant has worked in various NICUs in three states and provided invaluable insight into systemic and cultural differences across multiple units. The breadth of experience and rates of teen parent referrals differed drastically among study participants, ranging from a handful a year to 20-30% of annual NICU admissions. Further, participants in this study were recruited from level one NICUs (lowest acuity, basic newborn care), level two NICUs (advanced newborn care), and level four NICUs (highest level of acute care), and therefore their experiences and the services offered at each institution vary. Importantly, findings reflected differences in the demographic makeup of each institution. The

affiliated hospitals discussed in the interviews are considered urban or inner-city hospitals, catering to a diverse, lower income, or uninsured population, whereas others are described as catering to predominantly White and privately insured patients. Despite commonalities among each participant, their experiences must not be understood as generalized statements relevant to all NICUs nationwide, but as their own unique perspectives.

In order to meaningfully and efficiently report further interview findings, results are categorized by: 1) NICU providers' experiences working with teen parents; 2) resources offered during NICU admission; 3) resources and follow-up offered post-NICU discharge; and 4) what additional services and resources are of potential value.

Working with teen moms in the NICU: "Silence does not constitute understanding."

Among participants, the most commonly reported challenge regarding treatment of this population was parental engagement with services and acknowledgement of needs. Many participants described challenges associated with teen parents' ability, willingness, and readiness to utilize supportive resources. For younger adolescents, they are not of legal age to drive, lack transportation, or have limited financial resources to visit their NICU infants and rely on others in order to get to and from the hospital. Several participants reported a potentially greater impact of traumatic childbirth on adolescents and their capacity to engage in their infant's care following this. Others explained teens appear more reluctant to seek support or engage with their treatment teams out of shame or fear of judgment of their status as a teen parent. Two participants noted that older parents are more likely to visit the NICU, seek out physicians for information about their baby's status or care, and generally be more involved and collaborative with treatment teams. Another participant observed a tendency of adolescent parents to ask fewer questions of and interact with their physicians, which she attributed to potentially intimidating

power dynamics and discomfort around adults, although identified nurses as an exception. She added that young parents may not fully acknowledge their parental rights and their ability to make medical decisions for their baby; instead, their inexperience may cause them to rely on and defer to the treatment team. While most participants identified adolescents' dismissiveness or defensiveness as stemming from insecurities, one participant explained how providers' discrimination and judgment contributes to the relational dynamics. Several other participants also described strained communication between adolescent parents and medical providers, explaining that additional providers and more frequent conversations were required to educate teens about their baby's care due to parents' developmental level and degree of engagement.

A majority of participants described teen parents as "unrealistically optimistic" about the intensity of medical complexities, recovery, and parenting demands. While some believed this was a detriment, others saw this as a source of strength. One participant stated, "it's like they [teens] have no expectations and older parents have every expectation," making them more teachable, agreeable, and easy to work with. Another participant explained that their age and naivety is a protective factor, in that it shields them from acknowledging the severity of their infant's medical condition and may prevent emotional overwhelm or loss of sleep. Teens' degree of optimism also raised the issue of informed consent, particularly with younger adolescents or those without substantial family support, and provider concerns of parents' understanding of treatment.

Related to parental engagement and service utilization, participants asserted that social demands and parenting responsibilities are more conflictual among teen parents. As is developmentally typical for adolescents, young parents are eager to maintain friendships and socialize with their peers, potentially leading to less frequent NICU visits or significant

distractions that may be less interfering for older parents. One participant described her experiences working with teens who are “not able or ready to assume the role of a parent” and are “torn between teenage and adult identities.” This participant referenced substance use as a concerning factor, which she observes more often in younger parents. However, she noted that providers are more likely to drug test young and African American mothers and their newborns when placental abruptions occur, suggesting racial discrimination. Another participant identified logistical challenges, such as teen parents’ tendency to visit in the evenings when there are fewer behavioral health providers available to meet.

Another unique challenge described by participants was the navigation of multigenerational family dynamics. For some families, there is a significant role reversal occurring when the teen transitions into parenthood. In some circumstances, grandparents have difficulty promoting autonomy in their child and may continue to act as the decision-maker or authoritarian, rather than promoting and supporting their child to make informed decisions as the parent. One participant emphasized the importance of “orienting” the grandparents to their new role and helping them to balance their support and acceptance of their child’s parental responsibilities. This was described as prevention of grandparents “overstepping boundaries” or micromanaging their child. Enhancing the teen’s perceived capabilities and confidence as a new parent can be hindered by overly supportive grandparents, which may lead to overreliance, fear, and/or doubt that they can adequately care for their infant on their own. This is an especially fine line when teen parents are responsible for medically complex and fragile newborns. In other circumstances, participants identified the opposite concern of a teen parent’s overall lack of emotional and/or financial support when families are on “different pages.” Consistent with previous research, participants asserted that teen parents may have limited familial support or

support from the father if the pregnancy is unplanned. This is often the case when families are disapproving of the teen's decision to keep the baby, or when the parents were not in a stable, long-term relationship prior to the pregnancy. In such situations, the teen may become overwhelmed by parenting responsibilities and "forced independence," such as visiting their infant in the NICU with conflicting job or schooling demands, making important medical decisions without input from loved ones, and financial resources necessary for transportation, baby gear, and equipment. Another participant noted cultural differences in familial engagement, such that Hispanic fathers and grandfathers visit the NICU more frequently, whereas African American fathers and grandfathers are less likely to visit. This may reflect differences in parental or gender roles and acceptance of teen parenthood across cultures among other potential factors.

Similar to prior studies, interviewees reported greater concern of intimate partner violence and unsafe or unstable living situations among teen parents. Some may be forced out of their parents' home, have more strained relationships with family members, living with their partners or their partners' family, or staying with friends. As a result, teen parents are more likely to require the support of social workers or case managers throughout their admission, though it was noted this is not always reported by parents. Young parents may experience mistrust in providers out of fear that their infant could be removed from their care. These situations may lead to feelings of ambivalence, detachment, anger, anxiety, and/or isolation, which can interfere with treatment engagement. For example, one participant shared of a teen parent who was extremely conflicted about caring for her newborn due to the pressure from family to pursue adoption and appeared detached from her baby. However, multiple participants also reported a higher frequency of sibling or friend involvement. They described teen parents as more likely to have siblings and friends visit the NICU, which serves as crucial social-emotional support and

may increase teens' engagement in their newborn's care. While navigating family dynamics is not necessarily unique to teen parents, they may interfere with or enhance treatment.

Concerns of isolation were also frequently discussed. Several participants explained the rarity of having multiple teen parents on the unit at once. Being admitted to the NICU alongside older parents can increase a sense of isolation and make it more difficult to bond with other NICU families if teens struggle to relate to the experiences of older parents. Most providers noted that support groups, while intended to enhance connection and shared experiences among families, may further feelings of alienation or fear in teen parents. As a result, this could deter teens from participating.

Resources offered during NICU admission: "It depends."

All interviewees discussed similar NICU orientation practices and highlighted these practices as a crucial component of family-centered care, although few specifically address young parents. These practices include welcome or resource packets and NICU "boot camp," where parents are given tours of the facilities, lectures about different transition phases throughout their NICU admissions, and an overview of common conditions (e.g., complications of prematurity, developmental expectations). One provider explained NICU families can participate in a "parent panel," where NICU graduates share about their experiences, unexpected challenges they faced, and other helpful insights.

Most participants identified social workers, nurse navigators, and/or nurse coordinators as the initial points of contact with parents, who follow families throughout their NICU journey. Understandably, most providers explained that high-risk women (sometimes including teen moms) receive support prior to their NICU admission. One participant described a seamless transition of support from OB/GYN, to the Labor and Delivery (L&D) unit, to the NICU as a

result of nurse navigators following them throughout the course of this journey, rather than offering warm hand-offs to NICU-specific providers. Another unique resource one participant reported was music therapy, where therapists teach mothers how to interact with, soothe, and connect with their baby.

Several participants identified supportive resources that serve high-risk pregnant women and offer services in addition to standard prenatal care. One such resource is Nurse-Family Partnership, a voluntary, community health home visitation program for low-income, first-time mothers (Olds, 2003). The evidence-based program offers home visits from registered nurses beginning in pregnancy and continuing two years following birth. Another participant with extensive experience working with high-risk pregnant women founded a program for high-risk perinatal mothers (e.g., those with domestic violence histories, sexual assault victims, adolescent mothers, or mothers who have abnormal findings during follow-up visits), where they are paired with a nurse navigator to schedule prenatal appointments, schedule meetings with neonatologists, provide tours of the hospital and NICU, and offer general psychosocial support prior to birth. While this program is offered to many high-risk perinatal women, a subset of these eligible mothers are adolescents. Another provider described a family support group known as Love for Lily, a non-profit organization serving certain Colorado regions, which offers facilitated mother and family support groups, “essential bags” for families with anticipated NICU stays of more than two weeks, and even grants for uninsured families who spend at least one month in the NICU to help obtain therapies to support the wellbeing of their child or ease the burden of medical debts.

While support groups for NICU families are common practice in the area, they pose certain challenges. Multiple providers noted they are inconsistently attended, as parents often

prefer to stay in their infant's room while at the hospital. They also explained how difficult coordinating schedules can be and rarely do support groups align with every family's care schedules. Overall, however, the resources and services offered during families' NICU admissions largely depend on medical providers' perceptions of what the needs of each family are.

Resources and follow-up offered post-NICU discharge: "There's always a gap."

Findings suggest follow-up with all NICU families after discharge is rare. All study participants described limitations to post-discharge outreach as a result of funding and role restrictions, as NICU-based care understandably discontinues once families leave. One participant explained that their position is grant funded and is only permitted a total of five, 30-minute sessions throughout the admission before their care is transferred. Thus, systemic barriers make it difficult to continue treatment once families graduate from the NICU. One participant noted the transition home from the hospital is a critical time period where families often need more support.

Families are provided discharge packets that occasionally include mental health treatment options, such as local or national support groups (e.g., Postpartum Support International, March of Dimes, Hand-to-Hold) and programs and clinics (e.g., Colorado Adolescent Motherhood Program (CAMP) at Children's Hospital Colorado, Youth Mothers Clinic (YMC) at Children's Hospital Colorado, and Healthy Expectations Perinatal Mental Health Program at Children's Hospital Colorado). In some cases, teen parents may be referred to private practice therapists specializing in infant mental health or teen parenthood. One participant identified Florence Crittenton Services, a nonprofit organization that offers vocational training, education opportunities, and health care services to teen mothers and their children. Florence Crittenton

High School is a branch of this nonprofit organization and allows teen parents to attend school and provides childcare on site to ease the burden of parenting and education simultaneously.

Another participant noted that all NICU parents are asked to complete screeners for depressive and anxiety symptoms (i.e., PHQ-9, GAD-2) prior to discharge, and those with elevated symptoms are offered, at minimum, one session during their hospital stay and phone follow-up after their transition home.

However, discharge practices and resources offered were quite different. Some participants explained that discharge teaching is the only consistent practice prior to leaving the hospital. Discharge teaching includes education about signs and symptoms of newborn illnesses, how often to feed their infants, proper bathing techniques, and proper holding techniques. Only two out of five participants reported that teen parents are referred to the CAMP and YMC programs at Children's Hospital of Colorado. These programs are unique resources for young mothers and their infants, in that the parent-child dyads receive integrated medical and behavioral health treatment within the same medical home. Both CAMP and YMC aim to reduce repeat pregnancies improve the psychosocial needs and developmental outcomes of their families.

Additional services and resources of potential value: "We obviously need more."

Interviewees highlighted the need for more collaboration between NICU teams and community organizations to ensure a seamless transition of care for young parents. Few participants facilitate the coordination of care, and rather provide resource packets for families to seek out appropriate care if desired. Though it is common practice to require NICU infants to see a pediatrician within 24 to 48 hours after their discharge, it appears there is rarely follow-up done to ensure families get connected to the general practitioners, specialists, or behavioral health

providers of whom they were referred to. This suggests the need for more extensive research of service utilization, particularly for vulnerable or high-risk families (i.e., teen parents), and long-term outcomes.

Participants unanimously identified the need for online support groups. Online platforms are more feasible for NICU families given the limited impact it has on their time spent in the hospital. Online platforms, such as Facebook groups for young parents, may appeal more to a technologically savvy population and offer more ways to connect. Others identified a teen mom mentor as a potential resource for young parents in the NICU. Support from a non-medical professional and peer who has relatable experience in the NICU may enhance engagement of young parents. One participant described the potential utility of having a teen mother coordinator through Postpartum Support International. PSI enlists the volunteer support from Spanish-speaking coordinators, single mom coordinators, and military mom coordinators to offer support to parents with perinatal mood disorders and those navigating stressful circumstances with newborns at home.

It was reported that very rarely are Family Needs Assessments completed to learn of families' specific needs. Needs Assessments allow for treatment teams to individualize and tailor their care based on explicit requests from families. These may be conducted once at admission and once at discharge in order to improve support during their NICU stay and enhance coordination of care after they leave. Utilization of standardized, periodic screeners, such as the Edinburgh Postnatal Depression Scale (EPDS) (Cox et al., 1987), the Patient Health Questionnaire (PHQ-9) for Adolescents (Johnson et al., 2002), and the Generalized Anxiety Disorder 7-item scale (GAD-7) (Spitzer et al., 2006), may enhance the monitoring of young

parents' mental health symptoms during their NICU journey and inform care both during and after their hospitalization.

Research shows that mothers, fathers, and babies have an easier time transitioning home from the hospital if a good support team is in place. Enhancing postpartum services for young mothers may be one way to ease this difficult transition, and one participant identified postpartum doulas as potentially beneficial to young parents. Postpartum doulas provide evidenced-based information on topics such as infant feeding, emotional and physical recovery from birth, mother-baby bonding, infant soothing, and basic newborn care. In-home services, such as those offered through the Nurse Family Partnership and SafeCare Colorado, were identified as key components to ensuring the safety and success of young parents once they transition to the home environment.

Discussion

While a majority of these findings are consistent with empirical literature, results from the literature review and current needs assessment identify potential gaps in both research and clinical practice. All interviewees described similar resources and NICU practices consistent with the national standard of care. Findings from this study highlight that while there are intensive case management services offered to NICU families, there are rarely embedded mental health providers within the NICU and more often act as consultants, as would other mental health providers in integrated care settings. However, findings also implicate gaps in treatment specific to the needs of adolescent parents. A majority of participants shared about staff support and support groups offered across NICUs, although none are specific to adolescents and others are facility dependent. The current needs assessment suggests there are rarely multiple teen parents on the unit at a time; this trend complicates the creation of and questions the need for a

unified protocol for teen mothers. Given that the needs of each NICU family are different, individualized care is crucial and discrepancies in practice across different Colorado facilities are inevitable. Another significant finding suggests working with teen parents in the NICU is rare. This finding conflicts with the existing literature that identifies adolescents as at high-risk for birthing complications and NICU admissions; on the contrary, interviewees reported that teen mothers often have uncomplicated pregnancies and deliveries as a result of age and reproductive health, thus bypassing the need for critical care. Additionally, it is believed that increased access to long-acting reversible contraceptives (LARC) through the Colorado Family Planning Initiative has resulted in a 50% reduction in teenage pregnancies in Colorado. However, statistics show that nearly 40% of adolescent mothers have comorbid mental health conditions and/or experience psychosocial stressors, indicating that despite this funding opportunity and important initiative, ongoing barriers to LARC remain. These factors reflect the importance of closer monitoring and follow-up of young mothers' symptoms from the beginning, pointing to how crucial integrated behavioral health models of service delivery can be to improve long-term health, developmental, educational, and vocational outcomes of both young parents and their children.

It may be beneficial to implement periodic screenings of all young mothers' postpartum symptoms from the time of NICU admission through their discharge. Rather than receiving direct referrals from medical providers on a case-by-case basis, further integrating behavioral health providers in the NICU by making contact with all young parents may help reduce barriers to or stigma of behavioral health, enhance understanding of their individual needs, and potentially increase service utilization post-discharge. Establishing a collaborative relationship with mutual goals and a strong relational bond may alleviate a young mother's distrust or fear of

potential consequences if she were to acknowledge her stress. Further, the efficacy of peer navigators has been proven in adult populations, and based on findings of the current needs assessment, peer navigators or mentors with lived experience in the NICU may be useful to teen parents in order to enhance engagement and build trust with their medical teams.

Long-term implications and outcomes were rarely discussed in the current needs assessment. As teen parents constitute a high-risk population given the higher likelihood of adverse outcomes, further research must be done to understand long-term outcomes of those with medically complex and fragile NICU infants. Knowledge of such outcomes will inform NICU providers of what else must be done to care for teen parents and their infants during this very critical period of development. Awareness of follow-up care received, developmental outcomes, educational and vocational outcomes, and health status of NICU graduates can greatly affect what treatment the mother receives immediately following birth. Education is one of the primary roles of medical providers for adolescent parents in the NICU, as the success of the mother is thought to influence the success of the child; however, education must extend beyond parenting a newborn and include information regarding education, mental health, and intergenerational patterns that may have adverse effects.

Results from this needs assessment also reflected the lower likelihood of teen parents seeking out or engaging in treatment, which is well-documented in the literature. While in some cases this may interfere with parenting, in other cases it highlights teen parents' resiliency, confidence, and their desire for independence. Communication between medical providers and young parents can dictate their course of treatment post-discharge. As young parents are less likely to ask questions of their treatment team, communication must be free of medical jargon and encouraging of young parents to make decisions for their infants. Conversations must be

crafted carefully and honestly to avoid furthering power dynamics and reluctance of young parents to fully engage with their medical team. In line with family-centered care, all medical providers must acknowledge power differentials between themselves and families, as well as the potential impact of their status and physical presence in the room on young parents' willingness to engage, clarify, and decide on care for their infants. Bedside manner and culturally competent care is a demonstrated area of growth that particularly relates to working with adolescent parents facing stressful, high-stakes circumstances given the fragility of their newborns in the NICU. Further, direct communication with teen parents is crucial for ensuring they are aware of and making decisions for their baby's care. As some grandparents are involved in treatment, medical providers must recognize how this involvement may hinder the teen parents' engagement, confidence, and ability to care for their infants after discharge.

Limitations

The current needs assessment was solely conducted with NICU providers in the state of Colorado, which prohibits generalizability. It is impractical to assume NICUs across the United States serve one common population or have equal capacity to provide all resources outlined in this paper given the numerous differences across sites. Sociocultural context is extremely important to consider given the diverse demographic makeup of each NICU population, and this study captures the practices and experiences unique only to several Colorado institutions in the Denver metro area. The small sample size also narrows the breadth of information and richness of data, and the sample itself was comprised of only women, deeming this study as limited in its scope. Within this small sample were varied perspectives and experiences based on which institution each participant has worked in. While there were common themes and practices

highlighted in each interview, it is evident that some facilities treat more adolescent mothers than others, which can be dependent on level of acuity.

Opportunities for research into adolescent parenting in the NICU remain abundant. Adolescent fathers have rarely been the subjects of empirical studies, and given the historical difficulty of recruiting them to partake in research, further understanding of this population's experience of their parental roles would offer NICU providers more insight into how to effectively integrate them into their newborn's care. Similarly, studying cultural differences among teen parents with NICU infants may also provide crucial sociocultural context which can inform healthcare professionals of how to support young parents both in the hospital and when childrearing begins in the home. Longitudinal studies examining the health outcomes of NICU infants born to adolescent parents and service utilization might also help determine target interventions within and beyond the NICU. Additionally, studies exploring the impact of a premature birth, NICU admission, or medical complications on the postpartum course of adolescent parents compared to those with healthy babies may help redefine treatment parameters. Given the substantial strides to improve adolescent pregnancy outcomes in recent years, continued clinical and research efforts are promising and likely.

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Appendix A: Needs Assessment Interview Questions

1. At what facility do you practice currently? How long have you worked there?
2. Have you worked at other NICU facilities previously? If so, where and for how long?
3. Tell me about your professional experiences as a mental health provider working with NICU families
4. How long have you worked with teen parents?
5. When is a mental health provider's initial point of contact with families? What is the typical point of entry?
6. What services/resources are provided to families while their infant is in the NICU? (can include mental health resources, support groups, case management, etc.)
7. What have been your experiences working with teen parents? How often do you see teen mothers or fathers with babies in the NICU?
8. What are some differences in working with teen parents compared to adult parents?
 - a. How does family-centered care in NICU's include or exclude teen parents?
 - b. Biggest challenges?
 - c. Relationship with medical providers?
9. What is included in families' discharge packets? What mental health resources are provided to families leaving the hospital?
10. Can you identify gaps in services/resources for families during their NICU stay and following their transition home?
11. What additional services and/or resources do you feel would be beneficial to teen parents?
 - a. Are there any additional materials that could be disseminated to teen parents either during their NICU stay or in preparation for discharge?
12. What kind of follow-up do you conduct post-discharge?
13. What are your overall thoughts on how to enhance support for teen parents?
14. Are there other medical or mental health providers who I may contact to seek input from regarding these topics?

Appendix B: Resources for Young Parents in Colorado

Children's Haven: Teen Parent Program

A childcare center devoted to helping teen mothers continue their education.

Colorado Adolescent Maternity Program (CAMP) at Children's Hospital of Colorado

Children's Hospital Colorado's CAMP (Colorado Adolescent Maternity Program) Program is helping young mothers see pregnancy as more than a medical event. The program digs deeper and looks at not only prenatal and postnatal treatment, but also the social and emotional needs of young mothers and their families.

Florence Crittenton Services

Florence Crittenton Services is a nonprofit that educates, prepares, and empowers teen mothers and their children to become productive members of the community. We have been serving Metro Denver since 1893.

Healthy Expectations Adolescent Response (HEART) Clinic

HEART (Healthy Expectations Adolescent Response) Clinic provides care for pregnant and postpartum teens and young women with mood conditions. OB-GYN care is provided along with focused, ongoing psychological support, evaluation and treatment.

Hope House Colorado

Hope House is metro-Denver's only resource providing free self-sufficiency programs to teen moms, including Residential, GED, and College & Career Programs. Additional supportive services include parenting and healthy relationship classes, life skills workshops and certified counseling, all designed to prepare them for long-term independence.

Love For Lily

Love for Lily supports families in the Neonatal Intensive Care Unit {NICU} through facilitated support groups, provide grants for insured families who spend 4 weeks or more in the NICU to help obtain therapies that support the well being of their child(ren) or to ease the burden of medical debt. Love for Lily provides services and essentials to help families to thrive during and after life in the NICU.

Metro Caring

Metro Caring addresses immediate food needs of families living in poverty. This community organization provides nutritious groceries to families in need and offers comprehensive anti-hunger resources so that families can break the cycle of poverty. Metro Caring also promotes community activation efforts to address the food equity movement, offer cooking classes, diabetes prevention and management programs, assist with public benefits enrollment, and provide tax assistance.

Nurse-Family Partnership

Nurse-Family Partnership is a non-profit that transforms the first thousand days of life for babies born to moms living in poverty across the United States. Beginning during pregnancy, and until the child is two, nurses visit moms at home to educate them on parenting, share resources, and perform health checks.

SafeCare Colorado

SafeCare® Colorado is a free, voluntary parent support program for parents and caregivers with children ages five and under who need extra support to keep their families safe and healthy.

Young Mother's Clinic at Children's Hospital of Colorado

The Young Mother's Clinic is the only dedicated mother-baby medical home in the Denver Metro region. The Young Mother's Clinic provides a variety of healthcare services and resources to help young mothers and their children. In addition to caring for mom and baby's physical and emotional health, YMC provides resources to help support other family needs.

WeeCycle

WeeCycle is a Colorado-based nonprofit working hard to improve the lives of local families in need. We collect, "weecycle" and match essential baby gear to families through partner organizations focused on alleviating poverty, homelessness, domestic violence, teen pregnancy and under-employment. By "weecycling" baby gear, we help keep children clean and safe and contribute to a healthier environment for their future.