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Advancing Health Equity by Translating Lessons Learned from NICU Family Visitations during the COVID-19 Pandemic

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Introduction
Since its emergence in December 2019, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), also referred to as the novel coronavirus 2019 or COVID-19, has created a global pandemic. To date, there are over 15 million confirmed cases worldwide and over 4 million confirmed cases in the United States. (1) Although many questions remain unanswered regarding children affected by the virus, the pandemic has highlighted inequities in the US health care system and has demonstrated the potential of advocacy to influence policy changes. Although the pandemic remains a tremendous challenge, we present a perspective on how lessons we have learned during this pandemic may translate to further advocacy for equity in neonatal care.

As new data on COVID-19 are collected on both the national and international levels, guidance and policy changes have been rapidly developed and are evolving. Though this disease appears to be affecting children more mildly than adults, its rapid spread and disruption of the social infrastructure has affected advocacy and protective efforts for children worldwide. For example, policies on visitation in the NICU have varied widely in the United States and have continued to evolve throughout the pandemic. Although these visitation policies were implemented based on concerns for the safety of patients, families, and health care workers, the implications of these policies and the evidence to support them have been questioned by clinicians and family advocates. Such advocacy has led to positive change, and it brings to light the disparities that may be exacerbated by such efforts. We provide some recommendations on how to navigate
these lessons learned with a centering on the social determinants of health, and encourage others to critically examine further opportunities for change.

**NICU Visitation Policies During the Pandemic**

As hospitals and NICUs around the world began to confront the growing pandemic, restrictive visitation policies were implemented to protect patients, families, visitors, and health care workers. This has been a tremendous challenge for patients and their families, especially for women undergoing childbirth hospitalization and children receiving medical care. The Centers for Disease Control and Prevention suggested that “only visitors essential for helping to provide patient care and/or caring for pediatric patients should be allowed.” (2) Similarly, the American Academy of Pediatrics (AAP) has recommended that a limited number of family members and caregivers be allowed to be present for hospitalized pediatric patients. (3) Although difficult for families, restriction of visitors to the hospital, particularly in the setting of high COVID-19 prevalence, is a necessary component of reducing viral spread and an important public health strategy. However, some aspects of hospital policies introduced for this purpose may have been imposed in the labor and delivery department, nursery, and NICU without accounting for the unique nature of these hospital settings. (4)(5)(6)(7)

Policies surrounding NICU care, including visitations and breast milk provision, have varied widely across countries, in part because of a limited understanding of the pathophysiology and transmission of COVID-19. (8) We do not fault the cautionary perspectives in some settings, because of the many uncertainties and little evidence to guide policies at the beginning of the pandemic. (9) Early restrictive measures at larger, tertiary NICUs may have influenced the practices of their surrounding and affiliated NICU sites, some of which may have had limited resources. However, perspectives have evolved over time with increasing knowledge of the virus (both transmission and its effects) as well as increased advocacy and input from affected parents and caregivers. The degree of caution required has been curtailed as increasing evidence suggests that the risk of transmission in the NICU setting is low. (10) Conversely, depriving families of time for visitation and bonding with their infants introduces its own risks.

**The Benefits of Parental Presence in the NICU**

Policies that restrict family visitation in the NICU are particularly concerning because of the numerous recognized benefits of parental and caregiver presence at the bedside. Infants born prematurely and/or those requiring admission to the NICU may spend several months in the NICU, often separated from their parents and support system. During this time, infants and their families may experience multiple prolonged physiologic, social, and emotional challenges. It is well-established that infants admitted to the NICU experience significant pain and stress over the course of their stay. (11)(12) The NICU environment is one that is stressful and traumatic with noise, lights, procedures, and separation from parents. Yet, it is an environment in which...
premature infants must grow and thrive, reinforcing the need for resources and support systems that offer comfort to these infants.

The importance of parent presence and early interaction with their infant is well-supported in the recent literature. (13)(14)(15)(16)(17) Parent-infant attachment is critical for normal infant growth and development. (11) The quality of the relationship between infants and their caregivers plays an integral role in regulating the infant’s stress response. (18) Similarly, the beneficial role of early parental and caregiver presence has been documented in the neonatal population. Neonates are sensitive to maternal presence. Maternal-infant separation has been found to be a considerable stressor for neonates receiving care in the NICU. (16)(18)(19) When this early, supportive, and responsive relationship with a caring adult is nonexistent or minimal, the infant’s stress response remains elevated and leads to dysregulation of the stress response system. This ultimately undermines the infant’s habituation toward attachment and disorganizes healthy development pathways. (19) Prolonged exposure to stress in the NICU increases the risk for adverse neurodevelopmental outcomes. (20)(21) Better understanding of the effects of social isolation on long-term health outcomes and social attachments has led health care professionals to prioritize parental presence in the NICU.

With a push for more accommodating visitation policies, the benefits of minimizing parental separation in the NICU are now emerging. In California, the implementation of paid family leave policies was associated with a 12% reduction in postneonatal mortality compared with states without family leave policies. (22) A prospective cohort study found that infants who had increased parental visitation and were held more frequently demonstrated improved short-term neurobehavior. Specifically, infants with increased holding and parental visitation demonstrated less stress and arousal and improved motor development. (23) Collectively, these studies reveal the pressing need for visitation policies that permit parents and caregivers to be at the infant’s bedside in the NICU. This has been a well-understood priority in NICUs since before the onset of the COVID-19 pandemic.

**Role of Advocacy in Evolving Policies**

The COVID-19 pandemic has disrupted these priorities, requiring hospitals, clinicians, and families to question what actions and protections are necessary to ensure a safe environment. At the beginning of the pandemic, many hospitals implemented universal restrictions on visitation in the NICU. Some permitted only 1 parent to visit for a limited number of hours or for the entire duration of the infant’s NICU stay, whereas others required parents to trade off visits across variable periods. In response to these stressful restrictions, many parents shared their stories with their NICU teams and at the state and national level, calling for accommodations that would bring families together in a safe manner. (24)(25)(26)(27)
These calls proved to be effective, leading to more reasonable policies for parent and guardian visitation during the COVID-19 pandemic. Although these are encouraging developments made possible by many brave advocates, it is also important to examine how privilege, perhaps unknowingly, shaped these discussions and advocacy efforts. Both before and during the COVID-19 pandemic, our field’s commitment to protect family-centered care has struggled to provide for the needs of medically underserved patients and families.

**Risks for Exacerbating Disparities**
The admirable advocacy of many NICU parents and family communities has served as a reminder of parents’ roles as essential members of the care team. (27) However, we also need to recognize the risk of exacerbating current disparities in health care when hospitals are left to apply visitor policies on a case-by-case basis. Families who are financially strained and less able to advocate for themselves may be disproportionately harmed. Studies have shown that vulnerable populations may be at risk for suboptimal care, (28) and that the COVID-19 pandemic has significantly highlighted racial/ethnic disparities that exist across health care systems. (29)(30)(31)(32) Similarly, these disparities may be seen in NICU settings, for instance, with variations in the early implementation of strict visitation policies.

Disparities in NICU visitation have existed since before the emergence of COVID-19. Parental presence throughout a NICU hospitalization is greater among parents who are white and employed, compared with parents who are Black, socioeconomically disadvantaged, and on public insurance. (33)(34)(35) Hispanic and non-Hispanic Black mothers disproportionately cite challenges to frequent visitation including financial pressures, short maternity leave, other medical care visits, and inadequate childcare for siblings. Non–English-speaking mothers have reported overwhelming language barriers in navigating public transportation. (36)(37) These challenges to parental presence in the NICU—of costly accommodations, convoluted social infrastructure, and inadequate family support services—are a result of the compounding social determinants of health and its reinforcement of structural oppression and systemic racism. (38)

The rapid introduction and subsequent adjustments of visitation policies in the wake of COVID-19 were not immune to these inequities. The guidelines on COVID-19 visitation policies set forth by the AAP state that “any policy restricting visitors for pediatric patients should be applied equally regardless of children’s race, ethnicity, socioeconomic status, culture, and religion.” (5) However, the reality is that COVID-19 policy and public health responses disproportionately affect Black, Indigenous, people of color (BIPOC) communities, patients with limited English proficiency, and/or those of lower socioeconomic status. (39) For instance, some NICUs with seemingly strict visitor policies could make exceptions on a case-by-case basis. This can introduce inherent bias in patient care, and may largely benefit parents with greater privilege. Vulnerable populations may not have the ability or agency to advocate for similar exceptions. This may be, at least in part, because of a greater fear of visitation risks, which may be a difficult
realities for people with limited health care access or people working precarious and higher risk jobs. In such settings, such as in service jobs or field work, self-isolation and social protection are not always possible. In addition, the policies implemented by the NICU could be difficult to understand, especially if they were not readily translated into preferred languages and access to daily interpreter services was restricted given the NICU’s limited accessibility. Even before the emergence of COVID-19, many BIPOC communities lacked the financial stability needed to take time away from work, seek medical care, or partake in family caregiving. These circumstances, a manifestation of the social determinants of health, have come under greater strain in the wake of the pandemic, with a significant increase in unemployment, rise in food and housing insecurity, and sudden closure of essential infrastructures such as public transportation and school systems. (40) These circumstances, a manifestation of the social determinants of health, have come under greater strain in the wake of the pandemic, with a significant increase in unemployment, rise in food and housing insecurity, and sudden closure of essential infrastructures such as public transportation and school systems. (41)(42)(43)

In the NICU, the COVID-19 pandemic has undoubtedly introduced heightened barriers to parental presence and family-centered care for all families. Yet, we must remain cognizant of how these restrictions may disproportionately harm underserved and minority families. Even as hospitals and NICUs strive for transparent adjudication of visitation policies, this does not inevitably translate to equitable treatment in practice. In these pressing times, we must address the insufficient support for vulnerable families, and the ways in which well-intentioned advocacy may exacerbate the inequalities in health care. Reinforcing the essential presence of parents in a newborn infant’s care requires us to expand advocacy efforts to encompass all parents and families, challenging the inadequacies of the current social infrastructure so that we can better support vulnerable parents with the resources that they need to be present at their child’s bedside.

Concluding Recommendations
Though the current COVID crisis is ever evolving, it has and will continue to be our position as health care professionals to be the best advocates possible for our patients. This holds particularly true in the NICU because our patients are unable to express their own opinions, and decisions and desired positive outcomes may not be immediate or apparent. One point of emphasis is the need for equitable policies for parent and caregiver visitation that allows connection with each infant during the NICU hospitalization.

Furthermore, an increased effort in social programming to support families of hospitalized infants is paramount at this time, and will remain important long after this pandemic’s decline. In the midst of the NICU’s busy clinical environment, we may sometimes attribute lack of family visitation to circumstances beyond our control. By faulting factors such as employment, childcare, or transportation, however, we neglect the role we can play in advocating to change these circumstances. To provide the optimal care for our patients and families, our responsibility extends to the families that may not be able to be present and the barriers that keep them away. We must be stronger advocates, both for individual families and for broader policies at the hospital, employer, payer, and government levels. Horbar et al proposed interventions to reduce
racial and ethnic inequalities in preterm birth and create a culture of “follow-through” that accepts our responsibilities to address the social determinants of health. (44)

Our suggestions here apply not only to the current COVID-19 pandemic, but also after it has subsided. In accordance with the issues described previously, a needs assessment of parental and caregiver visitation in the NICU can elucidate the various barriers to their bedside presence. Whether because of socioeconomic hardships, communication differences, or other challenges in the home, it is apparent that multiple oppressive, and often intersectional structures create realities that bar families from being present at a newborn’s bedside in the NICU. Family visitation in the NICU is not only crucial for neonatal development and long-term infant-parent interactions, but also contributes to the overall therapeutic relationship between families and health care professionals. As the fight for equity grows in health care, we must critically examine the ways family and patient advocacy may unknowingly reflect or actively dismantle injustices. Combining these 2 parallel efforts may be difficult at first but is essential for improving the welfare of all children and their families. The Table lists potential actions to take to promote NICU and family advocacy for health equity.

The tremendous challenges of caring for a preterm or sick neonate, compounded by the pandemic, have reinforced the vital presence of parents and caregivers in the NICU. We encourage colleagues to use this momentum to advocate further for all families to be present with their infant in the NICU, not simply those who have the privilege to do so.

References

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### Table. Potential Actions of NICU and Family Advocacy for Health Equity

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<th><strong>Suggested Recommendations</strong></th>
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| **Patient-focused** | Provide multilingual, culturally relevant resources on benefits of parental NICU visitation and safety measures (related to COVID-19 during the pandemic, and generally, after the pandemic)  
Implement an assessment tool to identify social risks and address social determinants of health (SDH) needs of marginalized/vulnerable populations to combat health disparities  
Support quality improvement (QI) participation by parents including economically challenged, nontraditional and racially and ethnically diverse families |
| **Community-based** | Engage in advocacy efforts and community-based partnerships to support patients and families  
Partner with local food banks and nonprofit organizations to provide meals, transportation, and housing assistance to families during NICU visitations, especially if caregivers are unable to work  
Provide advocacy with local employers and insurers to allow for and expand family leave |
| **Institutional** | Promote culture of equity in the NICU setting with all clinical and nonclinical staff  
Strategize design of NICU unit with multidisciplinary team to accommodate families to visit (including adherence to COVID-19 infection control during the pandemic)  
Ensure that hospitals provide access to transportation and work alongside social work to develop childcare options for home or at the hospital |
| **State** | Implement quality improvement metrics and track outcomes for NICU visitation policies during and after COVID-19 across affiliated NICU sites based on race/ethnicity, sex, socioeconomic status, and community health |
| **National/regional** | Serve on state/regional/national taskforces that address NICU health disparities, and social determinants of health  
Advocate for Medi-Cal /Medicaid support for migrant and underserved families  
Promote social justice initiatives and health policy related to maternal and neonatal healthcare at the state/regional/national level | status to mitigate any health disparities |

Adapted from Horbar et al. (44)