

Our Responsibility to Follow Through for NICU Infants and Their Families

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In America, health and well-being are, to a large extent, determined by a person's race, ethnicity, income, immigration status, and neighborhood of residence. Racism, segregation, and inequality of income, opportunity, and wealth cause disparities in health outcomes across the life course.¹ The effects are particularly pronounced for infants requiring neonatal intensive care and their families because of the already significant risk for neurodevelopmental disabilities and need for specialized services.

As health professionals, pediatricians, and neonatal health care providers, we have the responsibility to address these social determinants of health. We must learn to practice social as well as technical medicine² and follow-through, accepting that our responsibility to the infants and families we serve extends beyond the hospital or clinic walls. Although in this article we focus on follow-through in the neonatal intensive care setting, the ideas for practicing social medicine we present have wider application in pediatrics, obstetrics, and beyond.

We have proposed the term "follow-through" to distinguish our proposal from the more typical neonatal practice of "follow-up" in which the services and staffing of clinics are focused, primarily, on medical conditions and assessment of neurodevelopment after discharge from the NICU. Only 70% of follow-up clinics provide any social services, for example, and <10% provide legal services.³ We propose a more comprehensive approach that begins before birth and continues into childhood, involving health professionals, families, and communities as partners to meet the social as well as medical needs of infants and families.

RESPONSIBILITY TO FOLLOW THROUGH

In proposing follow-through to the neonatal community, we have heard 2 main concerns. First, "this is not my responsibility. I am a physician, nurse, respiratory therapist, pharmacist, nutritionist, or other allied health professional. This is a social problem, something to be addressed and solved by government and society at large, not by me or other health professionals. Let someone else take this on." Second, "even if I accept that this is my responsibility, there is nothing I can do about it. I already have



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my hands full providing the technical aspects of bedside care.”

We argue that it is our responsibility to follow-through and address the social determinants of health with the same energy and expertise that we devote to the technical aspects of the care we provide. As citizens of a country that has systematically denied rights and opportunities to many of our fellow citizens, we believe that follow-through is our ethical responsibility. As a result of long-standing federal, state, and local laws and policies, Black and other minority Americans live in poorer neighborhoods, attend lower quality schools, and receive care at lower quality hospitals. Nontraditional, lesbian, gay, bisexual, and transgender families, and immigrant families face ongoing discrimination. We have the responsibility to do what we can to remedy the impact of past and ongoing injustices on the infants and families we serve.

POTENTIALLY BETTER PRACTICES FOR FOLLOW THROUGH

Vermont Oxford Network has developed 71 specific Potentially Better Practices (PBPs), to assist NICU teams to follow-through that individuals and teams can test and implement in their own units (Supplemental Information). We refer to improvement ideas as PBPs, rather than “better” or “best” practices, to indicate that no practice is better or best until adapted, tested, and shown to work in the local context.

The PBPs are divided into 6 main categories. Each category includes multiple ideas that teams can adapt and test in their own units. Users are free to mix, tweak, and build on the PBPs, with appropriate attribution under a creative commons license. We provide a few examples (Table 1).

TABLE 1 Examples of PBPs for Follow-through

Promote a culture of equity	Establish cultural sensitivity; acknowledge and manage implicit and explicit personal biases; facilitate nurse-led rounds
Identify social risks of families and provide interventions to prevent and mitigate those risks	Screen for social determinants of health; provide support when necessary such as assistance with housing, meals, and transportation and counseling for mental health, drug or alcohol problems, or smoking cessation; include social workers and legal specialists on teams
Take action to assist families after discharge	Provide carefully tailored discharge teaching; use home visiting and social media; establish meaningful clinical-community partnerships
Maintain support for families through infancy	Use parent coaches and innovative medical visit structures; provide contraception, family planning, and high-quality obstetric care; provide evidence-based early intervention programs
Develop robust QI efforts to ensure equitable, high-quality NICU and follow through care to all newborns by eliminating modifiable disparities	Establish measurable aims; engage all disciplines, parents, and primary care providers; obtain support from organizational leaders through a formal charter
Advocate for social justice at the local, state, and national levels	Ensure that social justice is part of every organization’s mission; advocate that health care organizations accept and act on their responsibility for the populations and neighborhoods that they serve; speak out!

Adapted from Beck AF, Edwards EM, Horbar JD, Howell EA, McCormick MC, Pursley DM. The color of health: how racism, segregation, and inequality affect the health and well-being of preterm infants and their families. *Pediatr Res.* 2020;87(2): 227–234. Additional PBPs can be found in the Supplemental Information.

Promote a Culture of Equity

Follow-through requires establishing cultural sensitivity in staff (PBP 2), acknowledging and managing implicit and explicit personal biases (PBP 3), and promoting a culture of equity (PBP 4), in which all individuals work to eliminate health disparities through respect, fairness, and cultural competency. A specific example of an action recommended by nurse leaders is nurse-led rounds focused on improving the patient experience and supporting culturally sensitive care for diverse populations. Purposeful nurse rounding requires empathy and deep listening for understanding, skills that must be modeled by leaders and expected of all staff.⁴

Identify Social Risks to Families and Provide Interventions to Prevent and Mitigate Those Risks

Follow-through starts when infants are still in the hospital, with screening for social determinants of health (PBP

8) and providing social support, when necessary, including mental health, drug, alcohol, and smoking cessation counseling (PBPs 13 and 14) and assistance with housing, meals, and transportation (PBP 15). Social workers and legal specialists, who are from disciplines not routinely represented in current follow-up clinics,³ can help address families’ problems and improve health equity outside of the hospital (PBPs 9 and 11). A successful example of legal participation on pediatric primary care center teams that can serve as a model for NICU teams is the Cincinnati Child Health-Law Partnership, a medical-legal partnership between Cincinnati Children’s Hospital Medical Center’s primary care centers and the Legal Aid Society of Greater Cincinnati. The Cincinnati Child Health-Law Partnership resolves legal issues common among families living in poverty, such as substandard housing, denial of public benefits, immigration issues, and intimate partner

violence.⁵ Attorneys with expertise in poverty and immigration law will be valuable members of multidisciplinary teams.

Take Action to Assist Families After Discharge (Transition to Home)

The transition to home is a critical point at which social factors must be addressed. Families leaving the controlled environment of the hospital will need to rely on their own skills, those of family and supportive individuals, and available neighborhood and community resources. Providing carefully tailored discharge teaching (PBP 23), assuring a medical home for families after discharge (PBP 26), using home visiting and social media (PBPs 32 and 36), and ensuring links to community services (PBP 29) are a few of the PBPs in this category. In some cases, meaningful clinical-community partnerships (PBP 41) may be necessary to change home environments. Administrators of Nationwide Children's Hospital in Columbus, Ohio, developed the Healthy Neighborhoods Healthy Families effort in recognition that the hospital's responsibility did not end once people left the campus. The beginning of the program was focused on improving housing; now, the program also addresses job training and leadership development.⁶

Maintain Support for Families Through Infancy

Our responsibility to follow-through extends into infancy and childhood. The use of parent coaches and innovative medical visit structures (PBPs 42 and 44) and providing contraception, family planning, and high-quality obstetrical care to improve outcomes for future pregnancies can help improve equity for children and their families (PBP 50). Evidence-based early intervention programs (PBP 43) are effective and should be routinely available to at risk NICU graduates.

Develop Robust Quality Improvement Efforts to Ensure Equitable, High-Quality NICU and Follow-through Care to all Newborns by Eliminating Modifiable Disparities

Quality improvement (QI) provides the ideal structure within which NICU teams can identify, test, and implement PBPs to address the social determinants of health. By establishing measurable aims (PBP 52), engaging all NICU disciplines, parents, and primary care providers on the teams (PBPs 54 and 55), and obtaining support from organizational leaders through a formal charter (PBP 56), teams will create the structure within which improvements can be made and tracked. An innovative QI program that achieved reductions in hospital days for children from 2 high morbidity, high poverty neighborhoods in Cincinnati, Ohio and could be adapted for NICU patients and families is an example of how QI methods can be applied successfully to address social determinants of health.⁷

Advocate for Social Justice at the Local, State, and National Levels

Finally, and perhaps most importantly, we must advocate for social justice, ensure that social justice is part of every organization's mission, and make sure that our health care organizations accept and act on their responsibility for the populations and neighborhoods that they serve (PBPs 62,63, and 68). A successful example of bringing together multiple stakeholders to address social justice at the community level is the Social Determinants of Health Taskforce for Baltimore City, a multisector voluntary collaborative action group composed of community organizations, government representatives, academia, urban planners, entrepreneurs, and health care system leaders working to address social determinants of health.⁸ This grassroots taskforce

works collectively to address and eliminate the negative social factors that are cyclical in nature, by collaborating with local community based and public agencies to improve health, housing, education, workforce development, and issues of social justice.

TIME TO GET STARTED

The list of Potentially Better Practices for Follow Through from the Vermont Oxford Network is intended as a starting point for individuals and teams. The PBPs vary greatly in ease of implementation and potential cost. Medical-legal partnerships are feasible but may involve additional cost, unless attorney resources can be obtained without cost, whereas implementing nurse rounds to address follow-through may be inexpensive and feasible, only requiring a dedicated champion. Hospital administrators and champions outside of the hospital may be required for some PBPs, such as clinical-community partnerships.

Our advice is to find something on the list that makes sense for your unit. Adapt a change idea to work in your local context. Test it. Start small. If others on your team are not ready, find a change you can make as an individual. Over time, we will learn together as a community how to most effectively practice social as well as technical medicine in the NICU. We will learn which interventions are most cost-effective and how to successfully implement them. The list of PBPs will be refined. The most important thing is to get started. By following through, we will play our part in addressing the inequities and injustices so deeply ingrained in our society, while improving the health and well-being of the infants and families we serve.

The coronavirus 2019 pandemic is exposing us to extraordinary challenges and disruptions in our personal and professional lives.

Health systems around the world are overwhelmed, with unknown consequences for pregnant women, newborn infants, and young families.

The social safety net is fraying. Unemployment is soaring. Community resources are stretched beyond the breaking point. Minorities, the poor, and those in living in disadvantaged neighborhoods with already insufficient access to medical and social services are at the greatest danger. Social distancing and staying at home are luxuries for the well-to-do. The racial and economic inequities deeply ingrained in our society will only be magnified.

We realize that as the pandemic unfolds, health professionals will be under extreme stress, heroically caring for infants and families in the face of significant personal risk and severe shortages of beds, equipment, and supplies. Although the comprehensive approach to follow-through described in this Pediatric Perspective will be impossible to provide in the near term, we must remain sensitive to the plight of the most disadvantaged among us and do

what we can to address their social as well as medical needs. In the aftermath of the pandemic, following through for patient and families will be more important than ever.

ABBREVIATIONS

PBP: potentially better practice
QI: quality improvement

REFERENCES

1. Beck AF, Edwards EM, Horbar JD, Howell EA, McCormick MC, Pursley DM. The color of health: how racism, segregation, and inequality affect the health and well-being of preterm infants and their families. *Pediatr Res*. 2020;87(2):227–234
2. Stonington SD, Holmes SM, Hansen H, et al. Case studies in social medicine - attending to structural forces in clinical practice. *N Engl J Med*. 2018;379(20): 1958–1961
3. Bockli K, Andrews B, Pellerite M, Meadow W. Trends and challenges in United States neonatal intensive care units follow-up clinics. *J Perinatol*. 2014; 34(1):71–74

4. Ogbolu Y, Scrandis DA, Fitzpatrick G. Barriers and facilitators of care for diverse patients: nurse leader perspectives and nurse manager implications. *J Nurs Manag*. 2018;26(1): 3–10
5. Klein MD, Beck AF, Henize AW, Parrish DS, Fink EE, Kahn RS. Doctors and lawyers collaborating to HeLP children--outcomes from a successful partnership between professions. *J Health Care Poor Underserved*. 2013; 24(3):1063–1073
6. Skinner D, Franz B, Kelleher K. How should health care organizations and communities work together to improve neighborhood conditions? *AMA J Ethics*. 2019;21(3): E281–E287
7. Beck AF, Anderson KL, Rich K, et al. Cooling the hot spots where child hospitalization rates are high: a neighborhood approach to population health. *Health Aff (Millwood)*. 2019; 38(9):1433–1441
8. Maryland State Archives. Task force on the social determinants of health in Baltimore City. Available at: <https://msa.maryland.gov/msa/mdmanual/26excom/html/04bcitysocial.html>. Accessed January 3, 2020

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