Not an Exclusive Club Anymore

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My childhood home in faraway Montevideo was a three-minute walk from the large and fancy National Golf Club. Access to the club and lawns was banned for non-members. On Sundays, however, the club would open its gates to the public, and city residents were allowed to stroll the fine grass extensions and enjoy the gift of a huge urban green area. As a child, I spent many Sundays exploring each and every corner of that seemingly immense green paradise. Nevertheless, for me, golf clubs remain emblems of exclusivity, elusiveness and unapproachability.

The first words of the target article title signal the topics of concern: “culture”, “research” and “communication”. Generally, we think “research” in neonatology involves the creation, dissemination, and application of scientific knowledge. In this case, it is scientific knowledge for the benefit of babies receiving care in a Neonatal Intensive Care Unit (NICU). But what does “culture” have to do with such science?

Our target article is authored by seventeen individuals, along with a Workgroup of the International Neonatal Consortium. Degl and colleagues take us on a look into NICUs scattered across the world and enable us to see some of the workings through three different sets of eyes. Each set of eyes belongs to a distinct group essential to the care of premature or medically fragile infants: neonatologists, neonatal nurses, and parents of babies that received care in a NICU. Other professions could have been included, but some important lessons were learned from just these three.

The data reported in the article came from a survey constructed systematically by a broad-based group using a stepwise consensus methodology. After a comprehensive literature review, the survey designers highlighted an important set of relatively unaddressed research issues: (i) preterm infants are routinely exposed to drugs that have not been adequately researched (for dosage, effectiveness, safety); (ii) investment in neonatal therapeutics tends to be low, and therefore lags persist in the study of new and existing drugs for newborns, as compared to other populations; (iii) there is a huge need to facilitate the conduct of neonatal clinical trials; and (iv) the participation in this kind of trials is perceived by many as potentially risky, burdensome for parents, as well as ethically challenging.

Then, with cloud-based software, the group administered an elegantly constructed survey to members of each “stakeholder group”, which yielded 323 respondents (52 neonatologists, 188 neonatal nurses, and 83 parents of NICU graduates) from NICUs around the world (see Table I in the article for demographics). They produced an article that is readable, with thoughtful discussion of results, supported by helpful data.

The results revealed differences in perceptions of the research process, research knowledge and its applications. How could this be among groups united by a common cause? A surprising number of parents were never or rarely offered meetings with the neonatal team caring for their baby—a setting where it would be natural and effective to share and explain research knowledge as part of the decision-making process. NICU parents have special forms of knowledge pertinent to research training and education programs, and yet, they were almost never consulted or included. Over 80% of the physician respondents felt that existing medications are insufficient to meet the medical needs of NICU patients; they cite unsatisfactory off-label use of medications, in untested dosages for babies. Parents and even neonatal nurses are relatively unaware of these shortcomings and the need for reform and guidance in appropriate pharmaceutical research. There were numerous other important revelations about the perception of research protections across the participant groups. Significantly, there was great unanimity across the groups, in support of the principle that research should be an important component of a NICU’s work.

The strengths of this report stem from the salient trends that are highlighted in it and reflected upon in the discussion. Indeed, Degl et al. provide a mind-opening perspective. Various questions are inspired by their article. How have we not contemplated and discussed these issues? Why have we been unaware of some of the real
challenges? What other summits have yet to be conquered in neonatal care that we have not even attempted yet?

Clearly, neonatal research is needed, as is its broadly-based dissemination. A NICU’s caregiving culture, along with family-centered developmental care, needs continued implementation and fine-tuning. In such a cultural context, input into new research directions will arise. Degl et al, preview some new and needed research questions. While the paper raises a variety of topics for reflection and action, I would like to address two extensions of the ideas in the target article that inspired me.

Envisioning a path beyond informed consent

While we can celebrate recent advances in patient involvement in medical research, parental involvement in neonatal research seems to be evolving more slowly. Informed consent is one aspect of neonatal research in which parental involvement is formally pursued. Since the ’70s parents have been asked to give permission for their babies to be involved in clinical research. Notably, the procedures for informed consent rarely have received input from the principal stakeholders, i.e., parents of NICU graduates.

Janvier et al.2 dig into the process of “informed consent,” beyond signing an agreement to participate. They emphasize the need to integrate parents in the review of procedures for informed consent and describe instances in which parental input improved how parents were approached for participation of their infants in research. They also identify further ways in which parents can be be integrated — from setting research priorities to analyzing and presenting results. Bourque et al.4 echo and extend these messages in their discussion of activities performed by resource parents in neonatology, and outline those activities where resource parents may be integrated to optimize research. Shen and collaborators6 note that researchers tend to restrict parental input to “later” stages of research, after the study focus has been finalized. They too, provide recommendations for engaging parents in research, and strongly advocate for the enhancement of research that is acceptable and relevant for the population it is intended to serve.

Visibility and clarity of research-related information

Degl et al.1 advocate for involving the “natural stakeholders” (namely, nurses and families) in NICU research in all stages of the research process. They see neonatal nurses as a crucial interface between families and neonatal research endeavors.

I emphasize the potential of increased parental involvement, as I believe parents in the NICU remain especially in need of advocacy. Fragile infants have fragile parents. But such parents are accessible and responsive. It is with great respect and admiration that we read a family’s testimony published in the most recent Developmental Observer, illustrating vividly how straightforward the enrollment process can be when a study’s objectives resonate with the values and potential benefits they envision for their child. Nevertheless, families might also experience profound dilemmas regarding enrollment.

Appropriately, we professional caregivers — each of us in our diverse roles — should be constantly aware that information that is clear and obvious to us is not necessarily so for families. Degl and colleagues identified the need for guidance in communicating with parents (and with nurses) about clinical trials, noting that education about research underlies effective communication more generally.

Questions about “what should we talk about with families?” often concern me, as there is much we need to discuss during an infant’s hospitalization. How much information can be handled by a parent in the NICU? It may seem daunting to add discussions of research to the topics we already address with families in the NICU. Here is a major lesson of “The Culture of Research Communication …”: communicating about research brings benefits. We move beyond the old and well known informed consent, towards a broader approach that advocates for parental involvement and engagement of a dramatically different kind. There are myriad benefits. Parents are empowered to parent. Staff are united and integrated. Barriers are broken. Inclusion reigns over exclusion.

Final thoughts

Where do we go from here? As a relatively young discipline, Neonatology has promising opportunities ahead. Research is needed to support and enhance neonatal clinical practices. In recent years, we have witnessed how the increasing involvement of parents in their infant’s care improves the care we deliver in the NICU.

Neonatal research may be our next “port of entry” into the advance- ment of our collaboration with families. This path is being envisioned for us by others.6,7 Imagine a culture of care that strives for more collaborative relationships among all the involved parties. Recall many of the parents you have known; dream of their involvement in redesigning research documents, developing research materials, prioritizing research topics, supporting recruitment and collection of data, coauthoring scientific articles, taking part in research committees, co-presenting at professional meetings (see Pyramid of Complexity, presented in Figure 1 in Janvier at al, 2019).6
Envision inclusiveness and collaboration, both in caregiving and in research. There is a view that can elevate and respect aspects of exclusivity. At times, “exclusivity” implies refinement or the privilege of high quality. But Degl and colleagues clarify the toll of exclusivity. At its root, exclusivity implies exclusion – denial of access. The future is already knocking at our doors. It is time. The exclusive golf club should be fully opened to all.

Acknowledgements: I am grateful to Jeff Alberts, PhD, for his thoughtful and invested support in the editing and organization of my manuscript. And to Ita Litmanovitz, MD, for suggesting thought-generating bibliography for my writing.

References