

Editorials

A final search resulted in another qualitative study. The theme that emerged from that work was that a father was “the practical guy in the shadows,” there to help but unprepared to face the challenges of the newborn period or unanticipated readmission (7). These themes are similar in the work of Sood et al (1). Tables 2 and 3 (1) contain particularly compelling comments. In the topic related to “insufficient finances/resources”, one father was quoted as saying, “Not having (spouse) income put everything on me...hospital food is really not that cheap..I didn't really think about how with (child) being born that all of the bills would come down to me.” When asked about “balancing responsibilities”, another father stated “while mom was here and baby was here they got support and they got help, but I was pretty much fending for myself” (1). Fathers described support systems through their partners, social workers, and spiritual resources; the representative comments did not include peer group interactions or other support networks.

At the core of this publication is the desire to provide patient-centered and family-centered care, the guiding principle of which is to listen to and respect each child and their family. Additional attributes are ensuring flexibility, sharing complete information, providing support, collaboration, and building on the individual strengths of the child and family (8). Progress is incumbent on including fathers into the conversations, decisions, and support networks.

This topic deserves additional investigation. Thoughtful study should address how we approach parents whose children are being raised by grandparents, whose mothers are deployed,

who are from different cultures, or who have same sex parents. Learning more about those who raise the children for whom we care will allow all parents to truly come out of the shadows and into the light of family-centered care.

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Do-Not-Resuscitate Orders and Overall Goals of Care in Critically Ill Newborns: Are We Always on the Same Page?*

I didn't want to kiss you goodbye, that was the trouble; I wanted to kiss you goodnight. And there's a lot of difference. —Ernest Hemingway

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Early reports on do-not-resuscitate (DNR) orders were first published more than 40 years ago in the United States (1). Since then, DNR policies rapidly spread in

*See also p. 635.

Key Words: do-not-resuscitate order; end-of-life decision; life-sustaining treatment; neonatal intensive care unit; newborn

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several other countries, becoming an essential tool for discussing about the resuscitation status of high-risk patients, regardless their age. Guidelines, recommendations, and position statements have been released by a number of healthcare organizations worldwide, both for adults and children (2, 3).

In the last 2 decades, advances in prenatal, perinatal, and postnatal care have dramatically changed the outcome of critically ill newborn infants, including extremely preterm babies as well as high-risk term neonates (4). Limits of viability have been increasingly extended, while term infants with previously fatal conditions may ultimately survive.

However, as caring for these sickest infants in the neonatal ICU (NICU), healthcare professionals must deal with even more difficult clinical and ethical issues, concerning decision-making on life-sustaining treatments (LSTs), DNR orders, and end-of-life care communication (5, 6).

Ideally, whenever a discussion on LSTs is foreseen, parental involvement should be sought at all stages of the decision-making process, to ensure that their opinions complete the perspectives clinicians may have, possibly sharing the overall goals of treatment.

In this issue of *Pediatric Critical Care Medicine*, Arzuaga et al (7) aimed to quantify and characterize DNR orders for critically ill newborns, released during the preceding 5 years in four North American NICUs. In addition, they prospectively assessed NICU staff experiences and beliefs with respect to appropriate medical management of patients with written DNR orders. They were interested to explore if the order of “DNR” in its current form allows for significant variation in clinical practice. Furthermore, they evaluated if NICU healthcare professionals received adequate training and education with respect to DNR orders. Despite some limitations inherent to the study design and a relatively low response rate to the survey (46%), the authors highlighted a number of important issues.

First, they observed a marked variation in practice associated with DNR orders, between different NICUs as well as individual clinicians. In two adjacent centers (Massachusetts), the DNR order was instituted just in the proximity of death, whereas in two other hospitals (Wisconsin), the interval time between DNR order and decease was more than twice as long, suggesting distinct policies despite a similar regional healthcare organization.

In other countries, end-of-life decisions could be influenced by various cultural and ethnic backgrounds. In a recent study, Chan et al (8) reviewed the modes of death in a large NICU in Hong Kong during a 12-year period. Out of 166 NICU deaths, only 13.5% patients had a DNR order in place, whereas nearly half of the patients eventually died despite active resuscitation. Of note, counselling for end-of-life decisions was only started in 59% of the families with deceased infants, reflecting a different approach being adopted by healthcare professionals in Hong Kong. Differently, in a prospective study performed in a tertiary NICU in Oman, a DNR order was written in about 50% of total deaths. Interestingly, the average time between DNR and exitus was about a week, much longer than that reported in the study by Arzuaga et al (7), which was around 1 day (9). Such marked difference may be related to diverse modalities of care before death, including different modulation of LSTs.

Second, clinicians' experience on discussing DNR orders and/or caring for infants with an active DNR order was very sparse. The vast majority of healthcare professionals were exposed to these situations less than once per year (7). As a speculation, these low figures may be partly explained by the relatively low occurrence rate of DNR orders in the four centers (0.3–2.5 per 100 NICU admissions) or a scarce involvement of nurses and residents during multidisciplinary discussions.

Third, a substantial proportion of respondents believed that the medical team could either withdraw (25%) or withhold (37%) medical interventions from a critically ill infant assigned with a DNR order, even if those actions had not been specifically addressed with the patient's family. Such observation may underlie a residual sense of paternalism within the NICU staff, particularly among the neonatologists. However,

parents' behavior and expectations have profoundly mutated in the last few years, and paternalism is no longer the way to go in many circumstances. For instance, in parents discussing to forego LSTs in the NICU, the perception of a shared decision was associated with lower grief when compared with a paternalistic decision-making (10). In other studies, parents appeared to be eager to play a role when the withdrawal or withholding of LSTs of their baby was under discussion. In a prospective multicenter study, Aladangady et al (11) observed a substantial proportion of U.K. parents who chose to continue treatment following discussions about limiting LSTs for their babies. Of note, some of these patients ultimately survived the NICU discharge, while a small number survived even after following the decision to limit LSTs (11). These observations raise big concerns about the risk of limiting LSTs in newborn infants with a “simple” DNR order in place, particularly if this choice is not thoroughly and transparently discussed with their parents. Some of these patients may eventually survive the NICU course, despite the presence of a DNR order, carrying the risk of suffering further damage due to undertreatment or suboptimal care.

Actually, DNR orders should apply only to cardiopulmonary resuscitation (CPR) scenarios, whereas other treatments and care should be maintained as appropriate, always focusing on the child's best interest (3).

But what does a DNR order really mean?

In a recent survey, Sanderson et al (12) explored the attitudes and behaviors of 266 clinicians regarding the DNR order. About 67% of respondents believed that a DNR order implies limitation of resuscitative measures only on cardiopulmonary arrest. Conversely, about 33% considered a DNR order as a sort of threshold for the limitation of treatments not specifically related to resuscitation. However, when asked about the implications of a DNR order, about 69% of clinicians reported that the care of a patient with a life-threatening condition does change once a DNR order is instituted (12). How can we explain such discrepancy? As a matter of fact, a DNR order may convey a strong symbolic value, both to the clinicians and the family, which may go well beyond the “simple” decision to withhold CPR in case of cardiac arrest, potentially shifting the overall goals of treatment from cure to comfort, thus involving other treatment limitations (13).

Finally, the authors provide information about an alarmingly scarce education and training among different healthcare providers, particularly in nurses. To face complicated discussions with families about DNR orders and/or provide adequate care for sick newborns with a DNR order, clinicians should acquire a high level of specific knowledge and skill, via continuing education and training in communication, ethics, and regional law (3). In particular, a good communication skill in these scenarios is essential and cannot be improvised or left to individual experience and beliefs (14).

Discussion on DNR orders and other important LSTs will probably be a matter of debate also for the next generations. Meanwhile, parents should be considered as the best advocates for their babies, at least in most modern societies, and their

full involvement in end-of-life discussions may help us to stay focused on what are the real overall goals of care for the baby.

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Is “See One, Do One, Teach One” Still Relevant in the 21st Century?

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Is the old maxim, “See one, do one, teach one” still relevant in the current era for teaching low-frequency but high-risk procedures? Few would disagree that bedside teaching remains invaluable training for physicians at all stages of their career, but does the apprenticeship model still, or did it ever, ensure that all trainees are achieving the necessary level of competence, regardless of their clinical experience? The Accreditation Council for Graduate Medical Education (ACGME) subspecialty requirements for pediatric critical care programs has for years stated that “fellows must become proficient in critical care procedures with patients sufficiently ill and sufficiently complex” (1), yet the challenge to ensure procedural proficiency for trainees is now greater than ever. The number of ACGME-accredited 1-year training positions

*See also p. 643.

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increased 80% over the past decade (from 121 in 2007 to an all-time high of 176 positions in 2015) (2), but has the number of patients each trainee cares for, and thus learns from, correspondingly increased by the same amount? Increasing shift work and shortening work hours decrease the traditional learning opportunities at the bedside even further. Thus, as our field increases the number of trainees entering the workforce, in an era of increased focus on high reliability and safety awareness in healthcare, do we need to do more to ensure that trainees in pediatric critical care receive the necessary skills to provide safe and effective care (3)? If so, what is the minimum number of procedures necessary to develop clinical proficiency?

In this issue of *Pediatric Critical Care Medicine*, Ausmus et al (4) report the findings of an internet-based survey of fellowship directors, fellows, and recent graduates in Pediatric Critical Care Medicine to assess trainee confidence in performing the pediatric brain death examination. Given that we have little published data on the scope of brain death examinations completed by fellows, the study by Ausmus et al (4) is quite informative. Of the 91 fellows that responded to the survey, 80% participated in five or less brain death examinations. Only 54% of fellows responded “agree” or “strongly agree” when asked if this was sufficient opportunity in training and only 60% agreed that they would be able to do this independently upon graduation. Interestingly, 90% of program directors reported that their trainees would be competent in performing these examinations, revealing discordance between the perceptions of fellows and their program directors.

The majority of instruction in performing brain death examination was varied and mainly happened at the bedside,