

## Responses from Annie Janvier and Bill Meadow to CMH Bioethics Center Slow Code Debate, 11/29/122

**Introduction :** The following questions were asked during the live video webinar and answered post-debate due to time constraints.

### **From Annie:**

Bonjour,

These are my answers to everybody. Please remember we were talking about neonatology and the NICU. Both Bill Meadow and I review all the deaths in our NICU. We know deaths in our NICU. I do to some degree in "our" PICU also. I really do not want people to understand that CPR is useless in ALL ICUs. NICUs are a different world. In the NICU, many babies stop breathing many times a day, and their heart slows down a lot = these are called apneas and bradycardias of prematurity. Nurses, when babies heart slows or becomes fast do not ring the code the majority of the time. In the NICU, babies very rarely die of fatal arhythmias, unlike in ICUs for adults. They die of their lungs most of the time, and cardiac massage will not bring the lungs back.

### **Question 1**

The issue here is TRUST. We must accept that no loving parents sitting bedside want their child's ribs cracked. 2. I believe that Dr. Meadow's use of normative deviance as logic to support slow codes is poor and dangerous logic... (question was cut off)

### **Meadow:**

I APPRECIATE THE QUESTIONER'S POSITION. PERHAPS THEY WOULD BE SURPRISED TO LEARN THAT SOME PARENTS "DO" WANT THEIR CHILD'S RIBS CRACKED. AND MORE TO THE POINT, MANY MORE PARENTS DO NOT WANT TO ACCEPT THE RESPONSIBILITY OF AGREEING TO "GIVE UP" ON THEIR BABY. THE QUESTION I'M ADDRESSING IS WHAT TO DO IN THOSE SITUATIONS.

### **Janvier:**

Barbara, I agree. Some conditions in neonatology are called "futile", but there are many definitions of futility...

### **Question 2**

Attendings are always present at the death of a baby with or without CPR. We do place DNR because we have had discussions resulting in that combined decision making with parents and others participating.

### **Meadow:**

IN MANY NICUS, ATTENDINGS ARE NOT ALWAYS PRESENT AT EVERY DEATH. WE TOO HAVE DISCUSSIONS WITH PARENTS. I AGREE THAT COMBINED, OR SHARED, DECISION-MAKING IS BEST.

### **Janvier:**

Not sure about this...Are you sure about this?? From speaking with many colleagues, this does not seem to be the case. I am certain many discussions happen. I am certain attending staff are caring individuals. Of course, if the baby is actively dying, the attending staff does not go home and leave the resident manage everything (I guess...). BUT many children are very sick and will probably die, and yet we continue intensive care because the parents are not ready to withdraw intensive care. If attending staff do not stay in house, it means they

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physically have to live less than 15 minutes away to actually be there at the “death” of a child... Unless really, CPR is done for 30-40 minutes until the staff arrives...

### **Question 3**

A doctor who consciously deceives is a deceiver. Today it might be medical futility, but who is next. A severely disabled child whom the doctor believes to have a "futile life" Where does it end?

**Meadow:**

THAT IS A THINNER VIEW OF REALITY THAN HAS BEEN MY EXPERIENCE.

**Janvier:**

Barbara, I agree. Some conditions in neonatology are called “futile”, but there are many definitions of futility...

### **Question 4**

We would never agree to "slow ECMO", "slow dialysis", or "slow cardiac surgery". Why would we do "slow CPR"? Why is CPR fundamentally different than ECMO, dialysis, surgery, or other interventions?

**Meadow:**

AN EXCELLENT QUESTION. BUT, IN THE U.S., CPR IS FUNDAMENTALLY DIFFERENT – YOU HAVE TO EITHER 1) CONVINCING FAMILIES TO AGREE TO DNR, 2) ORDER A UNILATERAL DNR, OR 3) PERFORM CPR. I DIDN'T INVENT THE U.S. RULES, BUT I AM TRYING TO GUIDE PHYSICIANS IN HOW TO WORK WITHIN THEM.

**Janvier:**

Are you sure there are no slow ECMOs? Time to decide if a baby really needs it, time to prime the pump. Never heard about it either, but I do not know, I have a fertile imagination... CPR seems to be different in the US, I realized it today more than anything... I think when we are talking of a baby “truly” dying (on 3 amines, pH = less than 7.0; no saturation in 100% oxygen and bradycardic = let's put it at its worse!), I do not sense that there is a problem not obtaining a DNR in my experience. We do not think about even getting it in my unit!

I think there is a big difference between CPR and the rest in the US because of this DNR order urge / need or necessity. There is no necessity to write in the chart: DNPECMO, DNPD, DNPCS... (do not provide ECMO, etc) ; there seems to be a need to write DNR in the chart of dying kids. Now, when kids are at home, I understand. In the hospital, I just don't get it....

Maybe if we started asking all our parents “this does not work, but we have to ask you if you want it”, I am not sure what would happen... So CPR is probably different because of the “need” for the DNR order.

### **Question 5**

What's wrong with "giving up" or giving in' when a disease outpaces medical skill and understanding? And saying so?

**Meadow:**

THERE IS NOTHING WRONG WITH 'GIVING UP' AND SAYING SO. BUT WHAT DO YOU DO WHEN THE FAMILY DOESN'T WANT TO GIVE UP? THAT IS THE ISSUE WE ARE DEALING WITH HERE.

**Janvier:**

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Not sure what giving up and giving in means... In my experience, we should not say there is "nothing" we can do. I am not sure we should tell families we are "giving up or in". We can always do a lot to make it better for families and their babies. But saying that we cannot fix and cure is indeed not wrong. Easy to say that the baby is dying, and our goal is add life to the minutes, and not minutes to the life.

### **Question 6**

What is the survival rate among babies with full, aggressive codes? With tailored codes? Do you share that information with parents?

**Meadow:**

IN THE CONTEXT THAT WE ARE DISCUSSING, THE SURVIVAL FOR BOTH FULL CPR AND TAILORED CPR IS ZERO. YES, WE SHARE THAT INFORMATION WITH PARENTS.

**Janvier:**

It depends who you are talking about. Babies less than 1000g = 0% (NEJM Lantos =0% = 0/48). For truly dying babies (on 3 amines, pH = less than 7.0; no saturation in 100% oxygen and bradycardic = let's put it at its worse), it is also 0%. For these situations (which were the situations we were talking about in the debate), a short, tailored, long, modified, etc codes have a 0% survival.

When baby is becoming a cadaver on respirator, in this situation, I do not tell parents all that does not work: another antibiotic for the resistant bacteria, G-CSF, a fourth amine, NO to 40ppm, ECMO, surgery, dialysis, etc... "you understand all these do not work, I am sure you do not want them, do you?" And I do not place an order in the chart indicating this. Why do we need to tell parents all that will not work for their child anymore, and order it? They are usually at the bedside, in my experience, they can see that we have deployed all our technological knowledge. We have spoken about death with the first amine and 100% oxygen.

### **Question 7**

CPR is really a procedure for a quick response in a serious medical problem. When babies have a lethal problem, then CPR should not be used. Do parents really want to have the doctors compress the chest/shock, etc?

**Meadow:**

USUALLY NOT, BUT AT TIMES YES. AND THOSE TIMES ARE THE ISSUE UNDER DISCUSSION

**Janvier:**

Lethal = we have to be careful about what we call lethal. Is it the actively dying baby (what the debate was about)

or a baby the physicians decided was not "worth it" (i.e. = a 22, 23 weeker, a 24 weeker...).

In my experience, parents do not want to have their dying baby die with CPR. It seems to be a cultural thing. It seems in some units, this is what parents want. The challenge would be to actually ask them down the road what they think about it. Ask many lay people, parents, patients, etc what they think. It is pathetic really that nobody has...

### **Question 8**

Doing 'everything' includes mutually exclusive entities -if everything is cpr it excludes the everything of holding, loving, peaceful family time - see Feudtner

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### **Meadow:**

I AGREE. THAT IS WHY WE TRY TO CONVINCe FAMILIES TO HOLD PEACEFULLY. BUT WHAT DO YOU DO WHEN THEY CHOOSE OTHERWISE?

### **Janvier:**

I agree. I usually do not say “everything” or “anything”. Parents want everything for their kids (in my experience, this everything does not include CPR). And yes, Feutner’s research, papers, ideas are great!

### **Question 9**

How often is the chaplain utilized as a partner when having these difficult conversations with parents?

### **Meadow:**

WE RARELY INVOLVE HOSPITAL CHAPLAINS IN THESE DISCUSSIONS. AT TIMES, FAMILIES BRING IN THEIR OWN SPIRITUAL ADVISORS, AND THEY ARE WELCOMED.

### **Janvier:**

We have a great “spiritual adviser” (who corrects us every time we call him a chaplain!), he is superb. We have a very high rate of atheists in Quebec, and he is amazing with families who are religious and also for those who are nonreligious. So our spiritual adviser is there in the NICU most of the day, even comes to difficult deliveries in the C-section room with us. Of course, some parents refuse his services, so not all parents benefit of his excellent services. Sorry to not have spoken about these partners in our team (I had 12 minutes; did you see how quickly Bill speaks?).

### **Question 10**

How does the provider who believes CPR will not provide benefit reconcile that medical judgment with the data about problems with prediction?

### **Meadow:**

A GOOD QUESTION, BUT THE DATA ABOUT PREDICTION OF THE SUCCESS OF CPR IS QUITE CLEAR. ABSENT ACUTE DECOMPENSATIONS (E.G., PNEUMOTHORAX OR EXTUBATION) IT DOESN’T WORK).

### **Janvier:**

The data about CPR in the NICU = it does not work. But you are right. Some patients are actively dying (on 3 amines, pH = less than 7.0; no saturation in 100% oxygen and bradycardic = let’s put it at its worse = i.e., when baby is bradycardic becoming a cadaver on respirator) = this is different from babies who are considered “futile” or “not worth” interventions.

### **Question 11**

What is the impact of cost to the hospital for either approach and how does this influence physician's discussion in giving options to families?

### **Meadow:**

THERE IS NO DIFFERENCE IN COST. DYING IS INEXPENSIVE IN THE NICU, WITH OR WITHOUT CPR.

### **Janvier:**

For the babies we (Bill and I) were talking about, dying babies on the respirator, cost is not an issue. Baby will die with or without CPR. With 5 minutes of CPR or 30 minutes of CPR, or no CPR. Epinephrine is cheap. For so called “futile conditions”, I think it is more a “not worth it”

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(value of the children) than economic value... but I may be wrong. Many babies are judged "not worth it" in American ICUs (23 wk infants, T13-18 babies); in the US, NICUs bring a lot of money to the hospital.

### **Question 12**

In this question of futile care for patients actively dying and physician vs. parent bias... I see many persistent vegetative patients who are "kept alive" for the value of a short life despite the fact that most adults would choose withdrawal of care for...(question was cut off)

#### **Meadow:**

MOST WOULD, BUT NOT ALL. FAMILY PREFERENCES ARE IMPORTANT HERE, EVEN IF YOU DON'T AGREE WITH THEM.

#### **Janvier:**

Complicated... do we want more for our babies and loved ones than we would for ourselves? Maybe? Also, rare to see babies in PVS.

Then predicting what we would want is another interesting field of research.... easy to say we would never want X or Y, but when X or Y happens, sometimes, we change our minds (of course, we could not change our mind if we were in PVS!).

### **Question 13**

What do you do if, when you tell the parents their infant is dying, they insist you start doing something to save the baby?

#### **Meadow:**

THAT'S WHAT A TAILORED CODE IS DESIGNED FOR.

#### **Janvier:**

Usually (in my experience which is different from Bill's), parents ask "what can we do? We are scared" "I am not prepared for this" "nooooooooooooooooo!" "This cannot be happening" "I cannot survive this!" "what should I do?" "are there coffins for babies that small?" Or sometimes, they do nothing, they just cry in your arms. I tell them our goal is add life to the minutes, and not minutes to the life. What would they want in their last moments? What would be important to them? What are important for their child? What will they regret if they did not do it, what scares them the most? These are questions you are not prepared for, parents are not prepared for the death of their children, and usually it is the other way around. This will not be easy. We will be with you. (This discussion is all about CPR that does not work on dying babies...)

### **Question 14**

Can it be clarified what medical interventions are actually offered to dying patients in the NICU in Canada?

#### **Meadow:**

I WOULD EXPECT THAT ANNIE DOES CPR THE SAME WAY WE DO IN THE U.S.; WHAT SHE IS ALLOWED TO DO, APPARENTLY, IS NOT PROVIDE CPR AND NOT ENTER A DNR ORDER – SIMPLY ALLOW DEATH. IN THE U.S. THAT IS NOT ADMINISTRATIVELY POSSIBLE.

#### **Janvier:**

I am speaking from my experience and do not want to claim to represent the whole of Canada. We have the same kind of palliative care, hospice care, surgeries that are available in the US. In our mother-child hospital, the pediatric palliative care service follows all the pediatric deaths

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that occur outside of the NICU-PICU, and many of the PICU deaths and some of the NICU deaths that do not die quickly or go home on palliative care. We have spiritual advisors, psychologists, social workers, etc.

### **Question 15**

For infants with Norwood procedures, we are seeing a lot of repeat ECMO placements. What do you think about slow codes for children who have been put on ECMO again?

**Meadow:**

ONCE YOU ARE ON ECMO, YOU HAVE TO DISCONTINUE IT TO ALLOW DEATH. THAT'S NOT QUITE A SLOW CODE.

**Janvier:**

slow codes for children on second ECMO after a first ECMO for HLHS? Slow codes for kids on ECMO (how much more max support do you want?). Wow! Hard question! Ever seen a survivor in this case? Why was the second ECMO started? We usually start ECMO for a failing heart... Not aware of one, but would need to check ESLO registry. If you call the ESLO registry, they would actually tell you if there are other children like your patient who survived.

### **Question 16**

Perhaps it's the US's emphasis on autonomy and informed consent.

**Meadow:**

YEP, THAT'S LIKELY THE UNDERCURRENT HERE. CANADA IS DIFFERENT.

**Janvier:**

I think you are right! Totally! There seems to be a need to present all patients with the "full menu" of what can be done, could be done, would not work, sometimes work... and this can be very confusing to patients. Also, parents take decisions with their hearts, not only rationally with their brains (check out my article, how much emotions are enough) and we seem to have forgotten that.

### **Question 17**

Do you view "attending" as the sole work of the physician? What is your experience in sharing attending with other staff members and are there any roles that you feel should be better integrated in the NICU? How much do you as physicians utilize the multidisciplinary team to help with your interactions with these patient's parents in situations such as these?

**Meadow:**

THERE ARE LOTS OF PEOPLE TO SHARE WITH, BUT IN THE END THE ATTENDING IS THE FINAL STOP.

**Janvier:**

Everybody in the team is so important for these moments. Nurses are angels, NNPs are amazing, spiritual advisors, palliative care providers, family members, psychologists, etc... I just realized that my talk did not include all these important people, sorry about that! Sorry for not mentioning my amazing colleagues who help us in these discussions and the many interactions parents have with them (much more than with the attendings!).

### **Question 18**

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How can you possibly even consider 'ambiguity' a version of truth? That would suggest 'watered down healthcare' on your behalf. Can you explain what then you mean when you say 'parents want you there?' do you mean just physically present?

### **Meadow:**

WE APPARENTLY DISAGREE ON THE BENEFITS OF BLUDGEONING PATIENTS WITH A SINGLE VERSION OF 'THE TRUTH'. PARENTS WANT YOU THERE PHYSICALLY, EMOTIONALLY, AND IN MANY OTHER WAYS.

### **Janvier:**

Will let Bill answer. I think we need to ask parents, lay people, parents whose child survived what they want. Many research we need to do!!

### **Question 19**

Dr. Meadow, what percentage of kids die in your NICU with no CPR of any kind attempted at any point? Dr. Janvier, what percentage of kids die in your NICU with no CPR of any kind attempted at any point?

### **Meadow:**

THE LARGE MAJORITY DIE IN OUR NICU WITHOUT CPR. MORE THAN 2/3. IN ANNIE'S NICU IT'S PROBABLY > 90%.

### **Janvier:**

Different patients, the Oops (mechanical problems) and dwindles (dying children) Children who die with CPR = 5% (last year examples = pulmonary hemorrhage, pneumothorax in PPHN, hemothorax, neonatal leukemia, CPR waiting for parents to arrive...) Of the 1500 admissions we have every year, we have about 30 real "CPR" (with chest compressions) per year in the unit. These are generally following an accidental extubation, a blocked tube, etc... one patient also had severe hyperkalemia.

### **Question 20**

Dr. Meadow: How do you address other requests for non-beneficial care, i.e. please keep my baby on the ventilator. How do you avoid unilateral decision-making in that situation?

### **Meadow:**

THOSE FUTILITY (NON-BENEFICIAL CARE) CALLS ARE DIFFICULT DECISIONS. AFTER ALL, KEEPING A BABY ON A VENTILATOR IS NOT FUTILE, IF THE DESIRED END IS LIVING ANOTHER MINUTE/HOUR/DAY.

### **Question 21**

For Dr. Janvier, You say that it's empirically true that the parents do not want CPR. If parents did want CPR, do you think then that slow codes would be defensible?

### **Janvier:**

Empirically, not sure. We should ask this to lay people, students, parents, parents of ex-preterms, parents of term kids, parents of dead kids, etc... it may be defensible if we give a lot of analgesia and parents truly heal quicker. But not sure, a parent wanting CPR to be the last moments of their kid's life is really weird to me.

In my experience, physicians do not need to explain to parents of dying children all the things that do not work. I do not have a compulsion to explain how we can sometimes restart the

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heart when it stops and that it would not work and please can you agree that we do not do something that does not work? If parents want CPR, why?

I have done one "short code" (was planning to do one round of epi after surfactant, this should take about 5 minutes) for parents in a special circumstance, after an extensive C-section, massive sacrococcygeal teratoma, 23 wk baby, hydrops, fetal descels. C-section was because baby was dying in utero, tumor too large for vaginal delivery, parents wanted to meet child alive for baptism. Baby was born without a heart rate and exsanguinated in the plastic bag we place around small babies for temperature control. Spiritual adviser was in C-section room with me. Parents wanted to try to "place a tube and restart the heart, just in case". Told them we generally do not do this, but I would try for them, in case. I intubated, gave surfactant and parents asked me to hold their daughter in their arms in her last moments after 3 min of resusc. (parents gave permission to talk about their daughter). I know it is not rational, but the large incision C-section made it hard for me and the special case (23 week with this large tumor, hydrops, DR resusc) to be 100% sure of "futility" of resusc. Short code is not a slow code. I would not lie or be ambiguous to parents in these situations.

### **Question 22**

Dr. Meadows, not being clear, offering a manipulated answer IS untruthful. I am an American, a professional but also a parent who lost 2 28 weekers. Should I have taken critical time to harass, grill & threaten the staff with legal action in order to...(question was cut off)

**Meadow:**

I AM SORRY FOR YOUR LOSS. I BELIEVE THAT THERE ARE MANY WAYS TO TALK TO FAMILIES.

**Janvier:**

Sorry to hear your story. I am the mom of a 24 week baby and was not lucky in terms of health care myself and my family. Maybe I am more indisposed by the need to lie to parents because we think they are not acting in their baby's best interest... my answer may be in part rational (and in part emotional!)

### **Question 23**

In NICUs in Canada, do you put your babies on ECMO and other such extreme treatments?

**Janvier:**

We have all the technology you have. We have heart surgeries, ECMO and all these things. Is ECMO extreme? What does extreme mean? It works quite well for meconium aspiration and post op heart surgery. I think it may seem more extreme depending on which patient it is done.

### **Question 24**

The Hispanic question/comment is a stereotype - from my colleague here with me Margarita Roque. Most of our Hispanic families are good decision makers.

**Janvier:**

Agree. Many stereotypes used when parents want interventions we do not think are in the best interest of their children: religious, poor, un educated, "difficult", "simple", "do not get it", "denial"... etc... we should stay away from stereotypes.

### **Question 22**

What research projects are you aware of that are studying parents' experience post-death?



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### **Meadow:**

EXCELLENT QUESTION – BOTH ANNIE AND WE ARE DOING STUDIES EXPLORING PARENTS' VIEW OF THE NICU POST THE DEATH OF THEIR INFANT. I KNOW OF NONE PUBLISHED.

### **Janvier:**

Jennifer Batza (a wonderful social worker in Emerson, Chicago), her colleagues and I are investigating parents (fears, concerns, etc) of babies with uncertain future. Some of the babies die and Jennifer meets them 18 months after the death, also sees parents of kids who survived. We also studied parental experience of parents of children who lived (many died) with T13-18. Please see our publication in Pediatrics.

### **Question 23**

I believe that you can make recommendations for the care of the baby without burdening the family. I.e. I "believe that medical treatment is no longer helping your baby and that CPR will not work. I recommend comfort care. What do you think?"

### **Meadow:**

I AGREE – GREAT IDEA. AND MOST FAMILIES AGREE. BUT WHAT DO YOU DO WHEN PARENTS DISAGREE?

### **Janvier:**

If that sentence works for you and your patients, I think it is great. (See related questions above). I do not personally mention all that does not work to parents of babies who are actively dying. Not sure we should say "I believe that CPR, surgery, more antibiotics, norepinephrine, something to help the blood pressure, more NO, the gaz we give to help with the oxygen, a surgery for the intestines that are necrotic..... will not work. " I am not sure when a baby is dying all these are important to mention, many things are important to talk about.

I try to adapt to each parent, there is no one sentence that works in all cases. It is like improvisation! Many parents and people who are not in the medical field do not know what comfort care is. Also, many parents who had experience with the adult pall care world react strongly to the words "palliative care", "morphine", etc... and explaining in lay language what is happening, what will happen, end of life practical issues (holding, music, spiritual, funeral, etc) is generally more helpful. Also, words are "just" words, there is so much more. The attitude, the time, physical presence, etc... all these are important.

### **Question 24**

A "tailored" code seems very much like a unilateral DNR, as the physician is deciding on offering only limited interventions. How are tailored codes really differ from a unilateral DNR ethically?

### **Meadow:**

THEY ARE DIFFERENT BECAUSE IN THE UNILATERAL DNR CASE, YOU ARE EXPLICITLY TELLING THE FAMILY THAT THEIR WISHES ARE NOT BEING FOLLOWED. AND THAT USUALLY MAKES THEM ANGRY – UNNECESSARILY IN MY VIEW.

### **Janvier:**

Tailored = what does it mean? Adapted to the patient? When a baby is in the DR and is born without a pulse, we try for 10-15 minutes (what NRP recommends). It is "tailored" to what NRP recommends. In the NICU, CPR is useless for a dying baby (does not work). It is useful for a baby who has an arrest following a mechanical problem (pneumoTx; extubation...etc). There

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are no recommendations for arrests in the NICU. For me, a tailored code when a baby is dying = no code! A short code is the last very bad alternative.

**Question 25**

Ensure I wasn't getting 'ambiguous" answers? It appears the 'ambiguity' goes against the very nature of the oath of practice taken. As a parent, I expect honest clear answers and choices, and then I will seek your opinion.

**Meadow:**

I DISAGREE. I AM ALWAYS HONEST, AND CLEAR WHEN FAMILIES WANT CLARITY. BUT AT TIMES FAMILIES CHERISH A SHOULDER TO LEAN ON, AND THAT'S ANOTHER PART OF THE OATH OF PRACTICE.

**Janvier:**

I agree. I am not ambiguous with parents. I did not want my physicians to be with me when I was sick, my kids were sick or my parents were sick.