My daughter, Rachael, has wanted me to have my “personal genomics” done since she learned it was possible. She is simply curious, but why do others want this information? Some want to expand their knowledge of their ancestry. Others want to learn if they will develop certain diseases or if they carry concerning recessive genes.

Certainly genetic information can provide powerful predictive information, but obtaining it through a physician or genetic counselor is time consuming, expensive and not always approved by insurance. There are a number of companies which will now do genotyping for individuals based on single nucleotide polymorphisms (snps) without a physician order. The benefits of using a direct to consumer test include accessibility, less cost and the ability to order online.

23andMe was founded in 2006. Their initial kit in the United States provided information on many diseases without physician involvement. This kit was removed from the market after the Food and Drug Administration expressed concerns. The new version includes ancestry information, carrier statuses, trait predictions and information on a few diseases. What is provided varies with jurisdiction and what

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The perspectives within the articles reflect the opinion of the authors, and do not necessarily reflect the perspective of the Section or the AAP.

On Direct to Consumer Genetic Testing
by Brenda Mears, MD, FAAP

is currently available.\(^1, 2\)

If you, the client, choose to do this, there are 19 pages of legal information and a 7 page consent form. If you choose to have testing done on your child, there is a link to talking points for discussion.\(^3, 4, 5\)

All this information is available to read at your computer. I somehow doubt many people read it. Among other information contained in these documents: you can consent or withdraw consent to research done on your information but the company says the database sifting work they do is not research on human subjects. They won’t sell your information without your explicit consent but they do share aggregate information about user genomes to third parties. They encourage clients to speak to a genetic counselor prior to sending a sample, suggest speaking to a lawyer prior to sharing the information with anyone, warn that if you deny taking the test when asked it might be considered fraud, and warn that you may need further services from a physician or genetic counselor.\(^4\)

The client must use the correct name and address and send the sample from the address used. The client must guarantee it is personal saliva and not from an insurance company or employer. As well, you agree to no rights to research or commercial products.\(^4\)

In short, you are paying them money to give you genetic and ancestry information and they will then use your data to do research and make money selling the data. We might be contributing to medical advances, but we are also paying money to give this company access to our genetic, health and personal information.

This summer, I went through this process. I read most, if not all, of the pages available on their website, collected a sample, answered their questions, and, sent them money. A few weeks later I received a link to results. Since then I have continued to receive short surveys asking questions such as “Are you red green color blind?” “How many nosebleeds a year do you have?” “Does cilantro taste like soap?”

I wasn’t convinced I would learn much. My family is in the, perhaps lucky, position that we know a good deal about my portion of the family history. We have a family tree which in one line traces to the American colonial period. The lines for which we have records are English, Scottish and German.

Anyone using this may learn some interesting things. When I first opened the information the week before writing this I had 1182 DNA relatives listed in their files. As of August 24, it is up to 1194. Most of my listed relatives are in the third cousin or more distant category. But I also found first cousins I do not know. (My father is one of the younger children in a large family.)

You can access paternal and maternal haplogroups, ancestry composition and Neanderthal ancestry. As expected I have a high percentage of Northwestern Europe ancestry, 98.2%. They test for 2872 Neanderthal variants, I have 295, more than 76% of their population. One of my variants is associated with short height. I suppose this might explain my fifth percentile height.

Carrier status is determined for a number of disorders including polycystic kidney disease, Beta thalassemia, Bloom Syndrome, Cystic Fibrosis and, Tay-Sachs. I am negative for all of them. Genetic health risks are determined for late onset Alzheimer’s (the APOE gene), Parkinson’s, alpha 1 antitrypsin deficiency and hereditary thrombophilia. I am negative for all of them as well. It doesn’t give information on other mutations such as the BRCA gene.\(^6\)

The traits and wellness section gives you your possibilities of having traits such as a second toe longer than the first toe or lactose intolerance. They are only possibilities so some are wrong. I have an increased probability of thinking cilantro tastes like soap. I do not, but my daughter does. I can even download the raw data if I wish.
On Direct to Consumer Genetic Testing
by Brenda Mears, MD, FAAP

This is a massive data gathering operation. Their web site states they have more than 2 million genotyped customers. 85% of their customers have opted in to the research portion. They have used individual survey responses to collect 600 million phenotypic data points. They state each individual contributes to over 200 research studies.¹

In consenting to this, I have in a sense consented for my children, my sisters and, my parents. I discussed this with Rachael but none of the others prior to testing. Did I have the right to consent for them without discussing it with them first? I decided this information does not belong only to me and sent the links to all 3 of my children. If my parents or sisters wish to see it I will give it to them but I find myself unwilling to share the detailed information with anyone else.

The only thing unexpected I learned was the Neanderthal gene information. Would I have found it distressing to know I might develop Alzheimer’s? Would I have had difficulty sharing this information with my parents, sisters or children? I don’t think so but certainly others might have problems. One thought is that the results should be given to an intermediary who can screen and review the results but this will certainly slow the process and decrease accessibility.

The company promises confidentiality but the information is out there. I have little confidence that it could not be hacked or pieces of information put together to locate me or my information. I have already received a message through the company’s message forwarding function from one second cousin (of whom I know nothing) wanting to compare family trees. I doubt it would be that hard to find me if she wanted to. When you google my name all but one listing on the first page concern me.

What happens to all this data if the company goes bankrupt? If I choose to withdraw from the program, can they possibly remove my data? Would they even try? If I take this information to my physician, will the information be placed in my medical record and be accessible to insurance companies? We don’t know.

For some people this program will cause unnecessary visits and costs for counseling or help interpreting information. Family secrets may come to light. It remains to be seen if the overall benefits outweigh the problems.

The persisting prevalence of moral distress, particularly within acute care settings, has resulted in considerable attention on the topic in recent times. Moral distress refers to the adverse emotional response experienced when an individual is prevented from responding in accordance with his or her moral judgment, due to factors outside of his or her control. Thus moral distress is generally thought to be intrinsically negative in its nature, threatening a person’s moral integrity. The negative impacts of moral distress have been well documented across healthcare disciplines including allied health professionals. Negative consequences include feelings of powerlessness, moral apathy and guilt that may impact the care of the patient and their family. Burnout and leaving one’s profession may ensue. It is thus understandably controversial and unpopular to suggest that moral distress may have some positive attributes. Yet this was the surprising conclusion of our questionnaire study looking at the perspectives of nurses and doctors within two neonatal intensive care (NICU) centers. Though the negative consequences of moral distress must be acknowledged and addressed, I will discuss why acceptance of a degree of moral distress is necessary in clinical practice and may actually improve patient care.

In 2016, prior to embarking on a longitudinal examination of moral distress, we wanted to know the nature of moral distress within our local neonatal units. We provided an anonymous questionnaire to all medical and nursing professionals at two tertiary level NICUs seeking their understanding and experiences of moral distress. The study highlighted the complex nature of moral distress: whilst the vast majority understood moral distress to be constrained moral judgment, they often additionally associated it with other forms of distress within the neonatal unit, most commonly including medical uncertainty or tragic circumstances. Surprisingly, whilst the majority of nurses and doctors experienced moral distress on at least a monthly basis, relatively few thought we should seek to remove all moral distress from our unit. This result seemed to reflect two themes: 1) moral distress was considered inevitable in the NICU due to the diversity of values and beliefs brought to the decision-making dynamic by both healthcare professionals and families; and 2) moral distress was viewed as an essential component of caring professions - reflecting a moral sensitivity to the complexity of the situation and a desire to act in a patient’s best interests, as well as acting as an impetus for rigorous and considered decision-making. We concluded that, whilst organisational reform is required to mitigate the negative impacts of moral distress (given its inevitability), we must also find ways to live with it and harness its ability to stimulate patient advocacy and promote considered decision-making that serves the interests of the patient.

The case for recognising the positive aspects of moral distress was recently argued by Carse and Rushton in their call for reorientation. They frame moral distress as evidence of ‘moral investment and energy’, and ultimately reflecting moral integrity in the quest to uphold moral standards and best outcomes for patients in our care. That is, the presence of moral distress reflects not only the negative element of being prevented from acting as one believes one should, but also the positive component of being sensitive to the moral issues at stake and having the integrity to uphold certain ethical values. Moral distress thus acts as an ‘alarm bell’ to a morally sensitive and attuned person, indicating that change is required, and may act as an impetus for progress. Here we see that there are two aspects to the positive nature of moral distress. First, the presence of moral distress reflects compassionate individuals who are morally attuned and strive to uphold certain ethical values. Without such individuals moral distress would not exist. Poor decisions would continue to be made with little moral consideration. Second, moral distress (though negative in that it indicates individuals feeling constrained in their capacity to act rightly in their own terms) can be used or harnessed to produce good by bringing to attention situations when care or decision-making could be improved, or prompting alternative views to be considered. Importantly, moral distress can only be an effective ‘alarm bell’ in promoting positive progress if it is situated within an ethical climate that encourages respectful and constructive dialogue without fear of retribution.

Within this positive reframing of moral distress, resilience is gaining traction as a tool for clinicians to modify the negative impacts of moral distress. Resilience encourages clinicians to redirect their energy from dwelling on the negatives of being constrained and assuming a victim mentality, to finding meaning in advocating for one’s patients, constructively challenging and refining decision-making and promoting improved patient outcomes. Resilience is not intended as the single solution to moral distress. Rather, it is a supportive tool that can assist clinicians while organisational issues and other contributing factors can be identified and addressed.

Yet the suggestion that moral distress may have some positive attributes is considered an unhelpful move by...
Accepting the Good with the Bad when Living with Moral Distress
by Trisha Prentice, MD

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some22. These authors believe resilience is not the answer: they argue that the use of resilience as a tool to reduce moral distress fosters clinician-blaming and suggests that those who are negatively impacted by moral distress are somehow ‘morally weak’ and should simply ‘buck up’22. Their position is that putting a positive spin on moral distress distracts from the systems or organisational issues that produce moral distress 23. Furthermore, they argue, harmful ‘constraints’ (which prevent clinicians from doing good) should not be required for good moral character to be recognised; and potential good outcomes from the symptoms of moral distress do not reduce its intrinsically negative nature.

Whilst I am sympathetic to the honourable quest to address root causes of moral distress, I believe we are at risk of causing more harm if we are not willing to accept the potential good that may be harnessed from moral distress along with the bad (the intrinsically negative nature of moral distress). We must appreciate that the ethical climate in which decisions are being made is constantly changing and evolving. Specifically, models of decision-making have changed from paternalism (where one person is solely responsible for the management decisions being enforced), to one of shared decision-making within a team environment where the values of the patient (or their proxy) and the views of the entire team are taken into consideration. Within this context, a reframing of moral distress is necessary to reflect the changing reality of clinical care. An over-emphasis on addressing organisational issues is not only futile but may actually foster the clinician-blaming that the proponents of this path wish to avoid. Let me explain in further detail.

Even if there is a perfect organisational structure in place where moral agents are empowered to voice concerns, seek ethics consults24, be heard by key decision-makers and assist in facilitating change, it is likely moral distress will still exist. This is a core finding of our survey. As individuals, we all bring different values and beliefs to our work place. At times these differences will result in genuine disagreement about what is the best course of action within the treating team. In a team-based work environment, this means that some clinicians, in fulfilling their professional duties within a team environment, may be required to act in a manner they consider not to be in the best interests of their patient. In this context, being heard and having your opinions genuinely considered and evaluated does not necessarily equate to an altered management plan or achieving the outcome that you desire. This is a reality of working within a team in an organisational structure. It does not necessarily count as evidence that there is a system failure or personal wrongdoing within the organisation. An organisational approach to moral distress will therefore not resolve all moral distress.

More concerning, though, is that such an isolated focus on addressing organisational issues may still result in clinician-blaming: the very thing that those advocating the organisational focus want to avoid. However, this time the clinicians in the firing line would tend to be those in perceived positions of decision-making power such as the physician acting in the role of clinical lead. Consider the classic cases of moral distress cited in the literature: a physician institutes aggressive clinical care, forcing the nurse to provide the burdensome treatment which that nurse believes to be not in the patient’s interests. The physician’s decision to continue aggressive treatment is the source of moral distress that must be addressed: it is presented as either a reluctance to recognize and consider the expertise of the nurse in question, or alternatively a reflection of the physician’s lack of moral courage to make the difficult call to redirect treatment to comfort care. Both implications are unhelpful and fail to reflect the complexity of end-of-life decision-making in highly pressured situations where there may be uncertainty about outcomes and multiple opinions and values in play. In such examples of moral distress, it is generally assumed that the nurse is accurate in his/her assessment that care is futile and thus disproportionate. Yet in reality there may be reasonable uncertainty or disagreement among team members as to expected outcomes. It is no more appropriate to blame the physician than to blame the nurse as being the cause of the moral distress. Moreover, as the nurse (in this example) remains fixed in his/her beliefs, moral distress will still ensue and demands attention.

Those against a positive reframing of moral distress argue that they do not expect consensus on every decision: “thank goodness for the keen eye of the attending physician who sees a ray of hope that the team does not see (yet)”22. However, under the framing of moral distress as an organisational issue that “demands systemic change22, the physician’s hope appears to be in tension with the fears of overly burdensome care experienced by other team members. Over time there is the potential for this astute physician to be unfairly labelled as the source of significant distress for those who are yet to ‘see’ the same hope, despite attempts to communicate his reasoning. He must choose between being seen to respect the expertise and views of his colleagues (i.e. that care is futile) resulting in threat to his own integrity, or uphold his decision and be viewed as the source of distress for others. Furthermore, he must balance the views and values of the family. The continuance of intensive care may reflect an attempt to respect the family’s legitimate role in decision-making and consider the family’s well-being beyond the life of their child, rather than being an indicator of moral weakness in the physician. Thus the

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by Trisha Prentice, MD

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outcome that may resolve moral distress for the nurse (i.e. redirection of care to palliative care for the child) may threaten the moral integrity of other parties – whether of the physician who believes all is not futile, or of the family who may hold alternative views on what is in the child’s interests. Current organisational accounts of moral distress frequently fail to capture these complex dynamics of moral distress.

Acknowledging some positive aspects of moral distress does not undermine its serious nature and real negative effects. Irrespective of the cause, the experience and consequences of moral distress are very real for the person experiencing it. Certainly we must continue to try and address organisational issues that contribute to moral distress but we must also take care to avoid attributing blame unfairly or transferring our distress to others - including upon the families for whom we care. Accepting that some moral distress may be inevitable due to moral subjectivity (rather than organisational issues) may help to reduce clinician-blaming, reinforcing the idea that alternative views may still be morally reasonable and also have the patient’s interests at heart. This in turn may foster mutual respect and understanding – conditions necessary for constructive dialogue and the creation of a safe environment where concerns can be raised without fear of retribution. In this context, resilience becomes about finding meaning in adverse circumstances and equipping clinicians with resources to deal with the inevitable hard situations that will come. This is does not equate to hiding genuine distress but rather is about finding meaning in reframing the situation and an openness to appreciating alternative views. Those who function from a framework of resilience may be better placed to be able to appreciate the value of discussion that moral distress has prompted, even when their views have been considered but not upheld.

Moral distress remains a prevalent and likely inevitable entity within acute care settings. Where possible, root causes including systems issues must be addressed to mitigate the negative impacts of moral distress. However, we should not be fearful of using moral distress to promote considered decision-making and medical progress. Such a positive reframing of moral distress assists in removing the victim mentality so often linked to moral distress and instead encourages collaboration, understanding, and a team approach to trying to mitigate the consequences. In this context, resilience is not a threat to addressing moral distress, but part of the solution.

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Going Beyond “Do-Not-Resuscitate.”
Is it Time for Comprehensive Orders for Life-Sustaining Treatment in the NICU?
by Bonnie H Arzuaga, MD, FAAP
Boston Children’s Hospital / Harvard Medical School

Cardiopulmonary resuscitation (CPR), as we know it today, was first developed in the mid-20th century as a tool to reverse anesthesia-related cardiac arrests in the operating room. For this indication, it was found to be very effective. By the early 1970s however, CPR was being applied to cardiopulmonary arrests attributed to a much wider range of etiologies. It was over this time period that the default action shifted away from allowing natural death to occur to attempting to restart cardiopulmonary circulation regardless of the underlying cause of its cessation. In response to this shift, efforts to clarify cases in which CPR should not be undertaken resulted in the creation of Do-Not-Resuscitate (DNR) or Do-Not-Attempt-Resuscitation (DNAR) physician orders.

In the present day, one-third of all pediatric deaths occur within the neonatal period and the majority of those take place in neonatal intensive care units (NICUs). In the past 30 years the frequency of DNAR orders has increased significantly in American NICUs and, more importantly, the percentage of infants who have a DNAR order in place prior to ever needing CPR has more than doubled.

Attempts to clarify DNAR orders have expanded into order sets which include specific interventions, such as Do-Not-Intubate (DNI), as well as instructions to abstain from certain interventions during a cardiopulmonary arrest, such as placing chest tubes or central lines. While this practice has led to improved end-of-life care with avoidance of unnecessary procedures in a patient’s final minutes, literature as well as anecdotal evidence has suggested that the meanings of DNAR orders are frequently variably interpreted by both physicians and nurses in the days or even weeks leading up to a patient’s death. My own work in the topic of NICU DNAR orders has shown that broad interpretations of what constitutes appropriate management of patients who have a DNAR order in their medical chart do indeed exist amongst NICU staff. Specifically, providers who have previous experiences withholding or withdrawing medical interventions for patients with a DNAR order are much more likely to believe this practice is acceptable, even in the absence of a discussion about such limitations with families or documentation that this approach is in accordance with families’ wishes. Staff demographic factors such as years of clinical experience, institution of practice, and previous education and training do not significantly affect their beliefs with respect to withholding or withdrawing treatments and interventions from patients. This suggests that the broad interpretations and application of DNAR orders may instead be a result of the order itself, in that it may not adequately provide staff with enough information to be able to best care for a particular patient. The order’s inherent emphasis on withholding CPR in the event of a cardiopulmonary arrest could theoretically lead some providers to erroneously assume that other limitations in care are not only appropriate but are also in accord with the wishes of an infant’s parents, which may not be true. There is robust evidence in the literature that adult patients with DNAR orders are less likely to receive clinically-indicated echocardiograms when in heart failure, be admitted from emergency departments to intensive care units, and are more likely to die even when all other confounding variables (including illness severity) are controlled for. Infants with DNAR orders in the NICU, whose conditions such as prolonged hypoxia and/or hypotension could lead to adverse neurodevelopmental outcomes, may ultimately survive. Therefore, withholding or withdrawing interventions such as supplemental oxygen or inotropic medications,

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by Bonnie H Arzuaga, MD, FAAP

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or failing to appropriately increase ventilator support, has the potential to have long-lasting permanent and devastating effects.

In most NICU settings there are typically many different people caring for a particular patient, including bedside nurses, attending physicians, nurse practitioners, residents, and fellows. In the many patient handoffs that inevitably occur under this model, overall goals of patient care that may have been initially discussed and agreed upon with an infant’s parents when a DNAR order was first placed can become progressively more misunderstood or even misspoken, akin to what we experienced during the games of “telephone” we played as school children. As a result, even with the best intentions and verbal communications, ambiguity can exist over which interventions or diagnostics are appropriate in the day-to-day or even hour-to-hour bedside care of a critically-ill infant.

So what can be done to clarify care for such infants in the NICU in a way that best honors the wishes and intents of their families? In the outpatient setting, recent work to develop comprehensive end-of-life care plans, known throughout the United States as either ‘Physician Orders for Life-Sustaining Treatments’ (POLST) or ‘Medical Orders for Life-Sustaining Treatments’ (MOLST), have been mostly successful.4 MOLST forms are being increasingly adopted by state Departments of Public Health in order to standardize the ways in which advance directives are written and then interpreted by Emergency Medical Services, emergency room physicians, and other physicians who may find themselves caring for patients with life-limiting conditions. States that utilize MOLST forms are reporting increases in both their use and provider awareness of their meanings, as well as better adherence to patient end-of-life preferences when compared to traditional advanced directives.

Successful inpatient use of a MOLST-like equivalent has been reported in a limited body of literature mostly out of the United Kingdom,5 but there are no studies describing how it may be used in a pediatric inpatient setting in particular. Given that the purpose of a MOLST is not only to outline whether a patient should have CPR withheld, but to further delineate, in specific detail, as many care options as possible, it has great potential to improve the way DNAR orders are placed and subsequently interpreted in a NICU. An effective NICU MOLST might include parents’ goals of care for their infant (i.e. comfort-focused, continued intensive care but no escalation, continued intensive care with escalation) at the beginning of the form with some level of case-dependent detail. This might then be followed by a section outlining specific interventions to be undertaken in the event of a cardiopulmonary arrest like chest compressions, chest-tube placement or epinephrine use. By de-emphasizing the CPR portion of a DNAR order and providing specific prompts for physicians to outline any desired limitations (or lack thereof) on day-to-day interventions, overall goals of care can be better understood by medical staff who may not have been present during the discussion with the infant’s parents. It would also allow parents and providers to ultimately become better aligned during the management of these infants by allowing them to work together to formulate a plan of care as clearly as possible while using a standardized approach.

References:
The perspectives within the articles reflect the opinion of the authors, and do not necessarily reflect the perspective of the Section or the AAP.
Talking about Disabilities—How Able are We?

Words can be stumbling blocks to good communication. That’s what I explain to our first year neonatology fellows in their “Intro to Communication” session. We discuss how different phrases or words can be value-laden and may unintentionally insult someone. Language may be overly-technical or lack precision so that parents don’t understand what we’re trying to tell them.

Conveying a message respectfully and accurately has proved to me a challenge at times when discussing disabilities. Apparently, this is a not a problem unique to physicians. In preparing to write this column, I found websites instructing journalists, college students, employers, and children on disability language. I think for a physician, however, needing to communicate a condition to parents as understandably and accurately as possible for the purpose of helping to set expectations or make decisions puts added pressure on getting our language choices right.

Section of Bioethics member Virginia Meade reflects on neurodevelopmental impairments (NDI), “Regarding explaining the risk for NDI to parents, I use simple language.” This is an approach I discuss with our fellows, too. Sometimes the best route takes a few extra sentences, but avoids medical jargon or insensitive terminology. I liken it to having a limited vocabulary in a foreign language—if you don’t know the right word, use the words you do know to describe what you mean.

However, parents will likely need more than a description of their child’s problem. They may seek information from other family members, other physicians, or from the Internet. I am amazed when Google can tell me the name of a movie after I type in the plot. However, for something as important as a child’s health condition, a parent will not find meaningful information from the Internet by entering, “my child may have difficulty walking” and would benefit from being able to enter their child’s specific diagnosis, such as “spastic quadriplegia.”

To that end, I’d like to explore some terms regarding cognitive disabilities.

**Developmental delay.** As medical professionals, we often use “developmental delay” and “disabilities” interchangeably. An August 17, 2017 email from Pediatrics Smart Brief had this tag line: “Premies have increased survival but developmental delay risk persists.” The article referred to “survival without sensory or neuromotor disabilities…” Would a hopeful parent view these in the same way? To me, a delay on the expressway is different than a closure. If I’m trying to help parents set expectations, I think I’d be doing them a disservice if I didn’t clarify whether the risk is waiting for a child to learn to speak eventually vs. the risk of never being able to do so.

**Mental retardation.** I thought this was an acceptable term to describe severe intellectual impairment. I thought the term “intellectual impairment” was too technical to use with parents. So naturally, I used this phrase when I participated in a simulation workshop at PAS last spring. I was role playing a physician telling a couple that their baby had Down Syndrome. In the debriefing, in addition to comments about my posture and eye contact, a co-participant said she was surprised I used the phrase “mental retardation.” At the time, I was embarrassed and thought I’d better avoid the term in the future. An interesting article about the shift from using “mental retardation” explains that to many people, the term “does not communicate dignity or respect and, in fact, frequently results in the devaluation of such persons.”

**Intellectual disability.** This term seems more accurate than “delay” and is more contemporary than “mental retardation.” While many recent journal articles use “mental retardation,” this newer term appears to be more suitable as it is belongs to the larger over-arching construct of disability while retaining its description of a more specific condition without pejorative undertones. A nice definition of “intellectual disability” is found in an AAP Clinical Report: “A disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains...Also referred to as cognitive impairment; previously called mental retardation.”

While “intellectual disability” may need a bit of explaining, it is at least a respectful and searchable term for a parent seeking more information.

Recent literature on consultations with families has highlighted the need to shift from the unidirectional model of physicians delivering information to one of shared conversation. Exploring what a parent or patient understands will help illuminate where our language fails. I recently used the simple-description approach with a couple preparing for extremely early pre-term birth. Dad’s question, “Are you saying my child could be disabled?” helped us in our exchange what he understood of the term and what the possibilities were for his baby.

Author Johann Wolfgang Van Goethe wrote, “A person hears only what they understand.” No doubt we won’t always find the right words, but asking what a parent understands should help us get them closer to hearing our message.

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Just an Expression?
Edited By Dalia Feltman, MD, MA, FAAP

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In the Spring 2018 newsletter, we’ll be exploring how we talk about treatments for conditions with very poor prognoses, reflecting on terms such as (but not limited to) “lethal,” “burdensome,” and “futile.” Ideas for future themes are always welcome—please share them with me at daliafeltman@gmail.com.

Reference:


http://pediatrics.aappublications.org/content/pediatrics/139/6/e20171002.full.pdf

Other links of interest on disability (both intellectual and physical) language:

From the ADA National Network: https://adata.org/factsheet/ADANN-writing


For journalists: http://ncdj.org/style-guide/

For University of Pittsburg faculty and staff: https://www.diversity.pitt.edu/sites/default/files/disability%20 każdej%20Language.pdf

Section on Bioethics

Ethical Stress, Virtues and Values Conflict in Pediatric Death
by Stephanie Kukora, MD- Janice Firn, MD- Patricia Keefer, MD- Naomi Laventhal, MD, FAAP
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Ethically challenging situations arise in providing care for critically ill and dying patients,¹ with amplified emotional impact when these infants and children die.² Consequences of repeated exposure to these types of ethical stressors can lead to significant burnout³,⁴ and compassion fatigue⁵,⁶ among bedside care providers, and compromise care they provide to patients.⁷ Though Hospital Institutional Ethics Committees (IECs) provide ethics support at an institutional level by resolving conflicts surrounding patient treatment decisions through clinical case consultation, only a minority of cases receive this comprehensive evaluation.⁸ Consultation with the pediatric ethics committee often is requested for cases that are prolonged, with values conflict occurring between the family and care team;⁹–¹¹ shorter, less complicated cases with nonetheless critical illness and tragic outcomes, and cases in which apparent values conflicts exist only among providers on the team, may also create ethical stress but not receive a formal ethics consultation. When clinical ethicists are not consulted, they are less available to address the routine, daily ethical needs of individual providers on the team; staff experiencing personal moral challenges in caring for a patient may not have a forum to voice concerns. Traditional ethics education focuses on knowledge and application bioethical principles to resolve dilemmas, and does not address personal ethical struggles, including values conflicts and moral distress. Current guidelines do not recommend strategies for imparting role-specific ethical knowledge to providers,⁷ and debate exists regarding how to ensure appropriate understanding and situational application of ethical concepts to all members of a healthcare system.¹²–¹⁴ Paucity of empiric evidence regarding the types of ethical stress providers encounter and the frequency that they experience it likely contributes to this conundrum.

Several studies have sought to qualitatively investigate moral distress and ethical dilemmas experienced by care providers for critically ill and dying infants and children,¹⁵–²² however, many of these studies have a small sample size, and few include multidisciplinary providers.¹⁵,¹⁷,¹⁹ The findings may also be influenced by recall bias, as providers are asked to recall a clinical situation in which they experienced moral distress/challenging situations¹⁵–¹⁷,¹⁹ or participated in care for a dying patient.²⁰,²¹

In an effort to address this gap, we surveyed providers identified through the medical record to have been involved in end-of-life care for an in-hospital pediatric patient, and invited them to share free-text thoughts and/or comments about the recent death. Using constructionist thematic analysis, we sought to identify whether providers remarked on ethical dilemmas or note moral distress without being specifically prompted to do so. We also aimed to characterize the nature of these dilemmas and distress if found.

In May of this year we presented preliminary results of this work at the Pediatric Academic Societies National Meeting in San Francisco. We analyzed 306 free-text responses in 879 completed surveys, between November 2014 and May 2016. These respondents commented on deaths of 138 pediatric patients, representing 81% of in-hospital pediatric deaths that occurred. The free-text responses were authored by diverse interprofessional providers, including: nurses, primary and subspecialty physicians and trainees, mid-level providers including nurse...
practitioners and physician assistants, respiratory therapists, social workers, spiritual care providers, and others. We found that although a minority of respondents described ethical challenges surrounding their patients’ deaths, 52 respondents, (17% of those providing free-text responses and 6% of all survey respondents), their comments described 38 unique patient deaths (27% of deaths captured with at least one survey response; 22% of all deaths in this time period). Our analysis identified two main themes: Ethical dilemmas addressed with traditional ethics education, and ethical dilemmas not addressed with traditional ethics education. In the latter, we identified two sub-themes: virtue conflicts and value conflicts.

Regarding ethical dilemmas addressed with traditional ethics education, several respondents discussed ethical dilemmas arising from their role as a provider in the patient’s end-of-life care. One described concerns about personal moral culpability in discontinuing life-sustaining interventions at the request of family members in a patient whose condition was stable on these modalities. This respondent expressed discomfort with uncertainty of outcomes/prognosis, including futility, and the gravity of making irreversible decisions. Similarly, a few respondents expressed concerns about inadvertently hastening the patient’s death when administering medications intended to alleviate suffering. These made up a minority of the responses, and it appeared that additional education on existing guidelines, including the AAP Committee on Bioethics statements on forgoing life sustaining therapy and bioethical reasoning on the topic of medication double-effect may have assuaged the concerns voiced by these respondents.

In terms of ethical dilemmas not addressed with traditional ethics education, multiple respondents specifically noted ethical stress in experiences surrounding truth telling, stemming from personal virtues of honesty and compassion in conflict. Experiences with truth-telling varied with perceived level of personal responsibility; those attributing responsibility for truth-telling to other care team members described moral distress, with discomfort arising from being complicit with an action they find morally wrong but are unable to correct, while those perceiving personal responsibility for the burden of honesty chose not to be truthful in their situations despite having the ability to take this course of action. Though from these comments it appears appropriately moral reasoning that in that specific situation--disclosure of the truth would have been more harmful than beneficial—the experience of being untruthful was sufficiently distressing to prompt respondents to commented on it.

The majority of the ethical stress reported described values conflicts, or disagreement with care provided based on personal perceptions of whether such care was in the patient’s best interest. In all of these cases, respondents expressed an opinion that care was inappropriately aggressive at the end-of-life; no respondents lamented that transition to comfort goals occurred prematurely. Notably, respondents exhibited varying levels of insight into values differences being the source of their distress, and those better at identifying values differences exemplified better coping. Providers with less insight into the presence of values conflict often attributed medical decision-making with which they did not agree to failure of physicians to educate families and assumed that no adequately informed parent would make choices differing from their own, and used very emotional language in their responses. We hypothesize that this stems from moral emotions, or the guilt, anger, resentment, or indignation an individual experience when they perceive that they or someone they care about has been wronged, offended, slighted, or harmed.

In our presentations at PAS, we posited that many interprofessional providers experience ethical conflicts with pediatric end of life care, but may not be willing or have opportunity to share these candidly. Though comments specifically describing ethical stress were provided by a minority of survey respondents, more than one quarter of the deaths in this time period had at least one provider comment on an ethical issue they encountered in providing end-of-life care. Only a few respondents in our study described ethical stress derived from common dilemmas for which guidelines exist. This suggests that at our institution, education and support around routine-ly encountered ethical problems with reasonably straightforward frameworks for resolution aid most (but not all) providers in these scenarios. Unfortunately, traditional ethics education and ethics committee services will not address the other two sources of ethical stress identified by respondents in our study.
We are hopeful that in the future, multi-center, multi-disciplinary studies of providers’ experience with pediatric end-of-life care will guide targeted education to assist staff in identifying and resolving ethical dilemmas encountered in these clinical contexts. Inquiry of all members of the interprofessional care team, as well as of patients’ families, will better inform provider training and improve patient care in these medically, emotionally, and ethically complex clinical situations. Further research is also warranted exploring alternative approaches in eliciting and assisting all providers on the care team with ethical stress in pediatric end-of-life care.6–27 These efforts might better support all care team members in resolving moral dilemmas and identifying values conflict in distressing cases in which the IEC is not formally consulted.

References:


2017 NCE Bioethics Sessions

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H2114– Joint Program: Section on Bioethics and Section on LGBT Health and Wellness

Date: Sunday, September 17, 2017
Time: 1:30PM—5:00PM
Hours of CME: 3

Description: Ethical Issues in the Care of LGBTQ Youth and Families
This session will examine legal and policy issues related to refusal of care for LGBTQ children and their families. In addition, the ethics of transitions for gender variant or transgender children, from early childhood through emerging adulthood, will be explored. A youth/ family panel will share their experiences in disclosing their sexual orientation and/ or gender identity to health care providers.

Agenda

1:30PM William G. Bartholome Award for Ethical Excellence— Award Presentation and Recipient Speech: Christopher Feudtner, MD, PhD, MPH, FAAP

2:00PM Expert Panel #1: Legal and Policy Issues in Refusal of Care: Conscientious Objection vs. Frank Discrimination

3:00PM Expert Panel #2: Ethics of the Care of Transgender Children from Pre-school to College

4:00PM Youth/Family Panel— Experiences of (Non) disclosure and Foregone Care

5:00PM Adjourn

Section on Bioethics

The perspectives within the articles reflect the opinion of the authors, and do not necessarily reflect the perspective of the Section or the AAP.
Bringing the State to the Dinner Table:  
The Impact of Health Care Access on the Ethics of Treating Childhood Obesity as Medical Neglect  
Jennifer Y. Seo, MD, JD

While American school children were on summer break, the Senate was active in drafting and attempting to pass various iterations of a new healthcare bill that would affect many of their access to health care. Namely, there were provisions to decrease Medicaid funding, which the AAP was vocal in opposing. Amidst the debates surrounding these bills, and timed appropriately with the start of the school physical season for pediatricians, the US Preventive Services Task Force (USPSTF) recently released a recommendation that pediatricians screen all children ages 6 and up for obesity and to offer or refer obese children to intensive behavioral interventions. 1 This recommendation, while confirming the evidence that the clinical benefits of such screenings and interventions outweigh any harms, does not touch on the realities of access to such services. Unfortunately, very few states ensure insurance coverage of obesity services, whether through Medicaid or through private insurers. 2 Cutting Medicaid funding would therefore decrease access to many children’s only available provider for obesity counseling—their pediatrician.

Given that obesity rates are higher among children of lower socioeconomic class, 3 that is, those more likely to depend on Medicaid, limiting access to pediatrician-driven nutrition, activity, and obesity counseling risks perpetuating high rates of obesity and its related comorbidities in this population. From a practical standpoint, at least a portion of the costs saved by decreasing Medicaid funding will likely be lost from the ongoing cost of treating obesity-related comorbidities. From an ethical standpoint, limiting access for those who need it the most seems to set up an already vulnerable population for failure, raising questions of justice. These concerns are compounded by the fact that while these children often rely on their schools to provide their best chance at a nutritious meal and a safe space for physical activity, holds are being placed on raising school nutrition standards in the name of cost-saving and physical education is being sidelined in attempts to raise math scores.

But recognizing that social constructs and policies perpetuate poor health outcomes like obesity among lower socioeconomic patients is not a novel observation. And how to best address the childhood obesity epidemic at all levels, including government, community, and individual, has remained a challenge. States have recognized the seriousness of the epidemic to the point of being willing to intervene in the care of severely obese children through the child protection system and to curtail, or even terminate, parental rights. 4 Proponents of using this method of state intervention have recognized the multifactorial etiology of obesity; however, they have argued that the cause of obesity, including resource and other social constraints, is not relevant because protection of the child is paramount. 5 Yet with ongoing threats of and actual reversals of health policies that attempt to address the childhood obesity epidemic, as well as data against the efficacy of removals of obese children from the home, the ethical calculus in these cases has changed such that concerns regarding justice and fairness should be given greater weight.

Childhood Obesity as Medical Neglect: An Imperfect Fit

The childhood obesity cases involving state child protection systems did so under claims of medical neglect. While there is no uniform legal definition of medical neglect and many states do not define it in their child abuse and neglect statutes, 6 the AAP Committee on Child Abuse and Neglect has provided a definition: “failure to heed obvious signs of serious illness or failure to follow a physician’s instructions once medical advice has been sought.” 7 Obesity, however, does not fall neatly under either form of medical neglect. And if it is thought that childhood obesity can and should be fit into the model of medical neglect, inadequate access to health care and other obesity-related resources puts resource-limited parents at disproportionate risk of being found to have neglected their children, though unintentionally.

First, it has been shown that half of parents underestimate their child’s overweight or obese status. 8 Furthermore, it is difficult, even among healthcare providers, to determine when or if a comorbid condition, like insulin resistance or fatty liver, will progress to a more serious state. Because of this, it is difficult to say that cases of severe obesity necessarily involve a failure to heed “obvious” signs of serious illness. Perhaps ideally obesity should be considered such an obvious sign, but if that is the case, those who have ready access to a healthcare provider who can help point out the obese status of their child would be at an advantage over those who do not.
Even with access to a provider who can inform parents about their child’s obesity, it does not necessarily follow that willing parents will be able to follow the provider’s instructions on treating obesity. The treatment of medical conditions is typically thought of as involving medications or a procedure that can be covered by medical insurance. The typical treatment for childhood obesity, however, involves healthy food, which is not covered by medical insurance and may be harder to obtain than medication depending on where the family lives. Moreover, while physical therapy may be covered by insurance, there is rarely medical insurance coverage (usually private and partial) for gym memberships or other fitness programs. And as with healthy food, safe activity spaces—free or otherwise—are often not readily available. Arguments in favor of finding resource-limited parents neglectful for not following through with recommendations regarding healthy food and physical activity also seem to overlook that the AAP policy statement on medical neglect lists as a necessary factor that “it can be demonstrated that access to health care is available and not used” for a finding of medical neglect. For resource-limited families, the usual obesity care may often not be used because it is in fact not available.

Proponents of using the child protection system in cases of severe obesity may argue that it is not obesity itself, rather the comorbid conditions that are at issue. The concerns outlined above, however, still apply. Certainly, parents who refuse to provide medications or allow for treatment of obesity-related comorbidities, for example insulin for diabetes or CPAP for sleep apnea, would fall under the medical neglect model like any other child with a treatable condition. However, proponents of viewing obesity as neglect, as well as the courts, have not just focused on treatment of the comorbidities, rather they have focused on caregiver failures to implement lifestyle interventions to reduce obesity. Thus, it is irrelevant whether it was obesity alone or its comorbidities that triggered involvement of the child protection system—the same access concerns remain. Disregarding the social constraints that may have contributed to a child’s obesity is a failure to adequately acknowledge the reality that many families have a lower level of support for treating obesity than for other medical conditions. And forcing childhood obesity under the medical neglect model risks disproportionate state disruption of lower income families.

These concerns of fairness are further bolstered by data regarding the obesity-reducing efficacy, or lack thereof, of removing children from the home. Both foster care and hospitalizations have been proposed and court-ordered for severely obese children. Unfortunately, both interventions have been found to lack long-term sustainability in reducing obesity. This results in a failure to meet a necessary condition outlined by Varness and colleagues prior to removal of an obese child from the home: a “reasonable likelihood that coercive state inter-

vention will result in effective treatment.” Removal from the home, therefore, with its disruption of the child’s family life and lack of a reasonable likelihood of effective treatment, seems to tilt more towards the side of harm than good in cases of childhood obesity.

The child protection system, of course, has other available remedies, including keeping a child in the home and connecting the family to more social resources. Yet why must we wait until a child gets to the point of being so obese that comorbidities set in and trigger a concern for medical neglect? The harms to the child’s health do not need further explanation. But it must also be acknowledged that the involvement of the state child protection system is, even if unintentional, by nature adversarial: state vs. parent vs. healthcare provider vs. child and all permutations of those players. This adds a real psychological harm to the already existing physical harm to the child—both harms that cannot be ignored and could have been prevented.

Conclusion

Despite the increased attention that the childhood obesity epidemic has received, obesity rates have remained stagnant over the past decade. This is undoubtedly in large part due to the multifactorial etiology of the problem, including the significant impact of poverty and limited access to health care and healthy lifestyle resources in the affected population. Unfortunately, recently proposed and implemented health policies seem to further perpetuate social disparities that promote childhood obesity rather than work to prevent it. Underprioritizing consideration of these social factors in using the child protection system to address childhood obesity, then, not only highlights justice concerns but also turns away from addressing a central and no doubt more challenging aspect of the problem. There may be a place for the state at the dinner table, but the state would better serve families by helping in the kitchen rather than showing up late and uninvited.

References:
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Please Contact Kelly Michelson, Editor, at k-michelson@northwestern.edu

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