

# Newsletter

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## From the Chair

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# Section on Hospice and Palliative Medicine



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## Culture and the Universal **Challenge of Coping with Death**

Birth and Death.

For as long as human beings have inhabited this wide world, our individual existences have been bookended by these two events; the alpha and omega of being mortal. And while no individual's birth was inevitable (indeed, guite the opposite; we are each the culmination of a mind-boggling run of chance), our deaths are absolutely inevitable. Moreover, for many millennia, we have known this terminal fact of life. In sum: Through all of historical time and in every

possible place, we humans have moved through our lives knowing that each life will end.

In this issue of the newsletter, which thematically addresses the role of culture in how people cope with dying and death, I emphasize both the universal, allencompassing aspects of death and foreknowledge of death because, in part, these days, I think we could all use a bit more appreciation of the fact that we are all in this thing called life together. The commonality of the challenges posed by death also illuminates the cross-cultural comparisons of how different groups grapple with these challenges. Finally, if we take "culture" to mean the values, beliefs, and practices that members of a group take to indicate the existence of that group, identifying certain shared aspects of cultural responses to dying and death can help guide clinical care alongside more culturally specific care elements.

Let me organize my thoughts around four themes identified in The Hour of Our Death by Philippe Ariès (Oxford University Press, 1981). In this masterwork on the history of dying and death in various Western European cultures over the past thousand years, Ariès, a social and cultural historian writes "this vast space

[of the history of death as he had surveyed the topic] seems to me to be organized around simple variation of four psychological themes. The first is the one that guided my investigation, awareness of the individual. The others are: the defense of society against untamed nature, belief in an afterlife, and belief in the existence of evil."



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Now, I must emphasize, these are themes that Ariès detected in so-called western civilization, and whatever that means, his study certainly leaves out most of the people on the planet. So, we cannot assuredly generalize across the globe. Nevertheless, these themes provide a starting point, and certainly illuminate how we in the United States "manage" dying and death.

For this article I have reformulated each theme into questions that I might ask a parent, seeking to explore how the themes are manifesting (or not) in specific families. In what follows, I am sure that we both know the importance of, and know how to, address each of these themes: asking and learning about the child and the beliefs and views of family members is a deep part of our clinical practice. What I am suggesting here is that questions probing these themes may accurately be viewed as a cultural attunement practice, which is to say, something we do to improve our understanding of each family's values, beliefs, and priorities across different cultures.

# Please Tell Me About the Child Who is Dying or Who Died?

Ariès' first theme, awareness of the individual, may be almost incomprehensible to us because we now live in such an individually oriented culture. But this orientation is, historically speaking, of recent vintage. While I think the notion that generations before the turn of the twentieth century did not bond with their children is overstated. There clearly is evidence that our current views of "priceless" children are quite modern (for a great exploration of this issue, see <a href="Pricing the Priceless Child">Priceless Child</a>, by Viviana Zelizer).

Equally importantly in our current historical era, each culture — each family within each culture — each member of each family within each culture — will understand and find meaning in the details that can potentially individuate each of us differently. There is nothing natural or "right" about how any particular family relates to a child — and thus, there can be nothing unnatural or "wrong", unless the family or family member sees the relationship as problematic, or the child is being neglected or otherwise harmed.

# What Personal or Group Acts of Caring or Rituals Do You Engage in?

Ariès' second theme, defense of society against un-

tamed nature, is linked to his observation that "... death was not [only] a personal trauma but an ordeal for the community...". In his view, since "death is not a purely individual act, any more than life is," the private space of death and dying (as we might view it now) has always been filled with different societies' various cultural attempts to cope with the challenges posed by suffering and our mortality.

These acts or rituals of care don't need to be public, although funerals and other services often are; individuals can perform caring acts or rituals quite privately. Still, much of what we do is informed or influenced by our culture, and specifically by this theme of trying to grapple with our mortal nature at the ends of our lives.

#### What Do You Think Happens After Death?

The third theme, belief in an afterlife, is not a universally shared belief, although it is widespread and common. Exactly what people think might happen after death varied dramatically over time in Ariès¢ study, and even more so across cultures and religions around the globe.

One important aspect of this theme that warrants attention in our clinical practice is how individualized these views often are, no longer prescribed by a particular religious dogma but instead pieced together, often quite idiosyncratically, by individuals, who may differ within families even if they share the same culture and religion. One will never know what others think happens after death unless one asks.

# Do You Think About or Worry About or Feel that You Need to Fight Evil Forces?

The last theme that Ariés addresses, belief in the existence of evil, is one that he singles out as conspicuously diminishing over time. And maybe he is right over the long view of time.

I am struck, however, by how often we encounter, explicitly or implicitly, people who view serious illness or progressive deterioration as some form of evil incarnate. Some individuals speak of this without prompting; others reveal their views only after some delicate probing questions. In such cases, understanding that the patient or family believes, at some level, that a struggle with evil is ongoing can be very important.

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#### Are You Angry? Who or What Are You Angry At?

There is another side to Ariés¢ final, perhaps dwindling, theme. As he puts the issue: "But if there is no more evil, what do we do about death? To this question modern society offers two answers. The first is a massive admission of defeat. We ignore the existence of a scandal that we have been unable to prevent; we act as if it did not exist, and thus mercilessly force the bereaved to say nothing of their loss." He then offers the second answer, equally troubling: "A heavy silence has fallen over the subject of death. When the silence is broken, as it sometimes is in America today, it is to reduce death to the insignificance of an ordinary event that is mentioned with feigned indifference." Ariés then reaches a macabre, counter-intuitive conclusion about the impact of a decline in the cultural belief in evil: "Either way, the result is the same: neither the individual nor the community is strong enough to recognize the existence of death." And if that was not enough, he notes: "And yet this attitude has not annihilated death or the fear of death. On the contrary it has allowed the old savagery to creep back under the mask of medical technology."

For me, my clinical spin on Ariés¢ own interpretation of his last theme is to inquire about whether patients or parents are angry, and if so, at who or what they are angry. The generic culture in the US (if there is such a thing) seems to provide the answer: to be angry at your disease. But this is often a problematic or unsatisfactory answer, as our knowledge of diseases becomes in many cases more genetic and or otherwise mechanistic, and as the difficulties of being gravely ill do not just stem from the disease or condition, but also (too often) from the medical care itself or the reactions of others to the illness. I find that often parents confide that they are angry, but are not sure where to direct their anger. This piece of information, like all the others that might be gleaned from the questions posed above, can guide us to understand and potentially help the children and families we serve.

All quotations in this article are drawn from Aries, Phillipe *In the Hour of Our Death* Oxford University Press, 1981.

# Grieving in Native American Culture of the Northern Plains

### By Lawrence J. Fenton, MD Sioux Falls, SD

Recently I had the opportunity of interviewing Ken James, a Native American chaplain on the staff at Sanford Children's Hospital in Sioux Falls, South Dakota. Chaplain James is an experienced chaplain who grew up in the tribal culture and served many years in law enforcement as a police chief and who now travels around this region ministering and teaching. He speaks both Dakotah and Lakotah languages. When we met, he held me spellbound for over two hours sharing his wisdom as well as his heart. The customs described are fairly specific to the tribes of the northern plains but some of the communication principles may apply around the country.

In communicating with Native Americans, he emphasized the importance of language. Even though most of us are unfamiliar with the native tongue, how we address people is vital to establishing relationship and rapport. Native peoples frequently reveal who they are through story or many stories. So when searching for a way to relate we must be prepared to listen long and well because so much is in the story. It is through the willingness to do this that we can establish a very important value, which is to make our Native American family/patient feel "visible." The depth of this word cannot be overestimated.

A second principle that should be recognized is the importance of kinship. The Native American may think of himself/ herself in terms of who their mother, father, grandparents, great grandparents and other relatives are or were. The sense of personhood may derive very closely from these relationships and therefore they are verbally honored both

publicly and privately. Communications between Native Americans may frequently include recognizing these relationships such that the words "grandmother" or "older brother" may be used when addressing more distant family members. An older person may be called grandmother - even though no relation - just to honor her.

Grieving is guided by the prophecy of the Sacred Buffalo Calf which states that: "The Honor of One, is the Honor of All and The Hurt of One is the Hurt of All." The powerful sense of community is recognized in this so that when there is a time of accomplishment, a joyous event, or a meaningful recognition the community shares in the feeling of accomplishment. Similarly, in a time of loss and pain or disappointment the community shares in those feelings and in both circumstances actively surrounds the person to either rejoice with them or support them in their grief.

Customs surrounding a death, whether of a child or an adult, include a 2 to 3 day wake that may be Traditional (led by a Native spiritual leader), Christian or a mixture. There may be a drum group with traditional singing during which it is important that people are touching and holding one another. Singing hymns in native language and praying in native language is valued and powerful. Following a death there is period of respect that may last 4 days or longer. It is a time when the presence of the deceased may be felt and appearances may be experienced and so it is a time when the bereaved are just quiet and respectful and thoughtful. Sometimes at the funeral there is a "giveaway" where

the bereaved family bestows gifts upon those who have attended. After a year a memorial ceremony called "wiping of the eyes" is held. The clothes and hair of the deceased may be burned at this time as a symbol that it is time to let go because it is thought that it is not healthy to continue to hold emotion inside. A dinner and another giveaway may occur at this time.

It is felt that the death of a child always brings with it an object lesson about life. It teaches about our own mortality and that our time on earth is unknowable and that all that we have has been given to us but for a time. There is a Native saying that at birth, the baby cries and the people rejoice. At death the people cry, but the one who died rejoices.

There is a Native admonishment about caring for children that goes: "Take care of our children. Take care of what they see. Take care of what they hear. Take care of what they feel. Take care of our children." A teaching that should resonate with us all as our children are exposed to violence, inappropriate language and abusive situations.

Chaplain James closed with this remark: It is said that "the longest walk in the world is from our head to our heart."

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# Cultural Competence: What is it and where do I start?

### By June M. Ganley, MSW, LICSW, ACHP-SW

Anne Fadiman's captivating 1998 book, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors and The Collision of Two Cultures*, highlighted the heartbreaking dangers of cross cultural medicine. Providing culturally competent care improves patient engagement, education, and satisfaction, and can help minimize racial and ethnic disparities in care. This article offers numerous practical resources to assist health care providers in our quests to provide more culturally competent care.

But first, what is cultural competence? As defined by Larry D. Purnell and Batty J. Paulanka in Transcultural Health Care: A Culturally Competent Approach (2013), "Cultural competence in health care is having the knowledge, abilities, and skills to deliver care congruent with the patient's beliefs and practices." Two key aspects of cultural competence are cultural knowledge and cultural humility.

The foremost reference on cultural knowledge is Purnell and Paulanka's literal textbook on the subject noted above. More portable options include Purcell's Guide to Culturally Competent Health Care, 2002 and Mosby's Pocket Guide to Cultural Health Assessment, 2007 by Carolyn D'Avanzo RN DNSc. Other respected sources of cultural knowledge, including beliefs related to death and dying include:

- The Handbook of Patients' Spiritual and Cultural Values for Health Care Professionals, 2013 available online at <a href="https://www.healthcarechaplaincy.org">www.healthcarechaplaincy.org</a>, and Religious Literacy Primer/Field Guide from the National Disaster Interfaiths Network, available online at <a href="http://www.n-din.org/ndin\_resources/">http://www.n-din.org/ndin\_resources/</a> FieldGuideSet.php.
- Lum, Hillary and Arnold, Robert, Facts and Concepts #216 Asking About Cultural Beliefs in Palliative Care.
   Fast Facts and Concepts, June 2009. See also these related Fast Facts: #17 (illness experience), #19 (spiritual history), #26 (explanatory model).
- For relevant information on the Lesbian, Gay, Bisexual & Transgender community, the Gay and Lesbian Medical Association www.glma.org has a free online webinar series.

While cultural knowledge is a good starting point, given intra-cultural diversity and to avoid the risks of stereotyping, providers must also have cultural humility- components of which include the ability to recognize the limits of that cultural knowledge, understanding one's own culture(s) and positionality, and having a nonjudgmental, genuine interest in learning about an individual patient's cultural beliefs related to health care.

Are you a member of the dominant United States culture of white, middle class, Protestant people of Northern European descent, or not? How does that affect people's perception of you, or your perceptions of them? What assumptions do you hold about people of other races? Those living in poverty? Without a college education? What are your beliefs about the purpose of suffering? How do you define quality of life?

Consider also the beliefs of the broader cultures of your practice setting and of Western medicine. Does your organization favor best practices or treatment innovations? Does it discourage acknowledging you don't know some aspect of care? How might these affect your perception of the patient, and/or your recommendations? As author and professor, Arthur M. Kleinman so aptly states in Fadiman's biographical tome, "If you can't see your own culture has its own set of interests, emotions, and biases, how can you expect to deal successfully with someone else's culture?" (Fadiman, p. 261).

Several enlightening exercises for examining one's own culture and bias can be found in Wintz (Sue) and Cooper (Earl)'s manual *Cultural & Spiritual Sensitivity -- A Learning Module for Health Care Professionals and Dictionary of Patients' Spiritual & Cultural Values for Health Care Professionals.* Pastoral Care Leadership and Practice Group of HealthCare Chaplaincy, New York, NY. Exercises 3,4,5,6.

Finally, providers must have skill in gathering a patient's relevant cultural information. This could be as simple as asking patients, "Are there any cultural or spiritual beliefs you have that are important for me to understand in this situation?" or for eliciting a patient's explanation

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and understanding of their illness, you can also utilize the well-known Kleinman's Explanatory Models Approach . Any approach is likely to fall flat however, if the provider is rushed, preoccupied, or otherwise disengaged. When a provider shows genuine and nonjudgmental interest in understanding the patient's cultural health beliefs, she/he evidences cultural competency, and may just improve care, increase patient compliance and satisfaction, and reduce racial and ethnic disparities - all worthwhile achievements for us as health care providers.

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Lum, Hillary and Arnold, Robert, Facts Facts and Concepts #216 Asking About Cultural Beliefs in Palliative Care. Fast Facts and Concepts, June 2009. \*Facts Facts are available online at <a href="www.mypcnow.org/fast-facts">www.mypcnow.org/fast-facts</a> or via phone/computer applications available for the iphone/ipad at the ITunes Store; and for android users at

http://www.getfastfacts.org Or play.google.com.

#### Additional Resources

CultureVision™ is an online comprehensive database that gives healthcare professionals access to culturally competent patient care that can be explored at www.crculturevision.com. Subscription required.

Courageous Parents Network offers Guides in Spanish, and videos are available in nearly every language imaginable thanks to You Tube.

#### To access the subtitles:

- Click the PLAY button, which brings up the icons in THE lower right corner of video window
- In the lower right corner, click on the CC (Closed Captioning) button
- Click on the SETTINGS button (Looks like a cog/ wheel), also in lower right corner.
- Click SUBTITLES
- Click AUTO-TRANSLATE and select the language you desire





## **Parent Corner**

# Interview with Sophia & Ross Zilber Written by Blyth Lord

**Sophia:** We have three boys. They're now 13, 10 and 6. Since we got married, we always dreamed of having a girl even before we had our first child. Maybe because we don't have any girls in our family. We had her name picked out before we even got married. Miriam. It's unbelievable that we already knew her name.

When I got pregnant with our fourth child, I would have been happy if it was a boy too, but when we found out that it's a girl, and everything is normal, I was so happy, I couldn't even talk. I just started screaming into the phone. I said, "oh, my God, I have to call my husband, I have three boys, I can't believe it's a girl!" It was just unbelievable how happy we were. I called Ross, I was screaming, I couldn't talk from happiness.

My pregnancy was absolutely perfect. All the ultrasounds were amazing. I usually don't buy things before the baby, but I bought a few outfits. I was just so excited that I can finally buy pink things. I got really cute things for breastfeeding, the cover-ups, with flowers. It was my last baby. I was 40 years old. It was like a gift for me. I thought I was making a major gift for myself.

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When she was born and I saw her, she was absolutely beautiful. I couldn't believe it. It was like I designed her myself. I remember calling my parents and saying, she's so beautiful. And Ross called his parents and I remember him saying, she's so beautiful. We felt so complete at that moment.

**Ross:** I wanted to give her name in a synagogue right away. It's a whole religious naming ceremony. Everyone had come in. Someone said, oh, this is the first time Zilber boys can produce a girl. And everyone was laughing.

**Sophia:** It's amazing that Ross insisted on doing naming in a synagogue for her so soon after birth. Looking back, it must have been a sign because if we waited longer, a month later she was already in the hospital and unconscious. She was here for such a short time, but at least we had a naming ceremony and a party for her.

From the beginning, something wasn't quite right with Miriam because she wasn't really breastfeeding. I always had such a good experience breastfeeding my boys. I told nurses in the hospital when she was born that this is my fourth child and it was so different before. I didn't think it was anything serious. I had no idea even that these diseases exist. I was so naive. They just kept saying that she'll figure it out, sometimes it takes a little longer. And then she didn't gain weight as much as she should have, even though she wasn't losing weight either. So it tricked the doctors, I think because I was working very hard on feeding her. I literally was feeding her 24x7. I would go to the pediatrician almost every day to weigh her. Eventually I had to switch to a bottle. But she wouldn't take the bottle either, which I showed to the pediatrician. She said, keep working really hard, keep working harder. And these doctors are so experienced, our practice is so experienced. Looking back, I just can't believe that they didn't think something was wrong.

The first few days she cried a lot, but then she went to the other extreme. She stopped crying. She was so lethargic and she would always sleep. I called my pediatrician and asked, are you sure it's okay, she was crying so much and now she's too calm, she's not crying. And my pediatrician said, well, she's just happy with everything.

One Friday afternoon, I told the pediatrician, maybe I should take her to Children's Hospital just for them to look at her. I felt very uncomfortable going into the weekend when I couldn't feed her. The pediatrician looked at me and said, there is really nothing for them to check. So I went back home; I felt so helpless. On Sunday morning her skin felt very cold. I didn't realize at the time but her body temperature was dropping. She was actually dying, which we didn't know then. We gave her a bath, which was crazy, because I thought it's going to warm her up. She slept through the bath. Water was pouring on her and she was sleeping. After the bath, I noticed that her hand was puffy, like there was some fluid or liquid in it. I had no idea what it meant, but I felt some intuition. I just thought, 'I have to take her to the doctor now, something is going on.' When we got to the doctor, she called the ambulance right away because Miriam's vital signs were all horribly low.

**Ross:** When we got to the hospital, they were waiting for us and started running around, like on a show. They put her on life support for her breathing. They told us most likely it's an infection.

**Sophia**: We have a friend who is a doctor and he was texting with us late at night. I remember texting him that doctors said if it's not an infection, it's a metabolic disease. And he texted back, well, that's very rare, you shouldn't think about it, that almost never happens.

Next day they did an MRI. They called us into a meeting with the doctors. They said they want to talk to us about the MRI. When we came in, we saw a very long table with many doctors there and social workers and nurses. They all stood up and didn't sit down until we sat down. And when I saw that I thought, oh, my God, something is very wrong. And then the neurologist said, we want to talk about the MRI with you.

That meeting plays in my mind still -- forever. Every word of that meeting -- it's still playing in my mind. The doctors told us that that it's mitochondrial disease. They were very pessimistic. They told us that it has no cure or treatments. But it was good that they told us the truth. We wouldn't want to be given false hopes.

**Ross**: They are able to see high lactic acid in her blood

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and they were able to see high lactic acid on the MRI in her brain. They didn't know yet which exactly disease it was. Later we knew it was Leigh's Disease.

**Sophia**: They told us that if Miriam starts breathing she would come back home, but her life would be very short. At that point I was thinking about my boys and what it would do to them to have her back at home, knowing it was only a matter of time.

We went home and told the kids that Miriam is very sick. We told them that she might not get better. It was truly the worst thing I had to tell my kids. I broke their hearts completely. They wouldn't stop crying for most of the night. It was killing me that I had to hurt my children this much. But I had to tell them the truth because I had to prepare them. And they started praying for her. They prayed for her so much, really. Especially my older son, who was 12. He would just pray for her for hours.

Our friend is a neurologist. She told us right away that Miriam most likely has Leigh's Disease. She also told us if Miriam starts breathing and comes back home it'll be a "different Miriam". She told us that Miriam's hand was likely puffy because she was retaining fluid.

**Sophia**: In a few days they did another MRI on her and it had gotten so much worse. The neurologist was crying and told us that Miriam is dying.

The doctors said that we could remove the breathing tube.

We talked to our Rabbi. First, we asked what are we supposed to pray for now that they told us she's definitely dying. Can we really still pray for recovery? What do I tell the kids because they are praying so much and it's helping them to pray? He recommended telling the kids that God already made his decision for Miriam, but they could pray for strength, they could pray for God to do his will. That was very helpful for us because it helped us accept what was happening, but still pray.

Next, about the life support -- our Rabbi told us that by the Jewish law, we really can't take out an intervention that's already there. He also consulted with another senior Rabbi and they really took it very seriously. If she had never received life support, we wouldn't have to give her breathing tube, but now that she had it, it should not be removed.

**Ross**: Actually, they would have recommended not to intubate her in the first place, if they knew her diagnosis.

**Sophia:** One nurse asked us, Does your Rabbi think that she'll recover? And I said, No, he understands, we know that she'll die, but we'll just let God take her away and not do it ourselves because if we are the ones that pull out the breathing tube then we are technically taking the action to end her life. Our Rabbi recommended we shouldn't take active actions to shorten her life, but we also shouldn't take active actions to prolong her life. For example, once her blood pressure starts falling, we don't have to give her medication. We signed the DNR.

**Ross**: Rabbi was there every day and all the time he was consulting with the senior Rabbi in New York.

**Sophia:** It took a month, a little over a month. That was absolutely the hardest month ever. We knew that we could always technically stop.

**Ross**: We could do whatever we wanted to do, it was still our decision as parents.

**Sophia:** Our Rabbi was in the hospital almost every day for hours. If I texted him that I'm really upset, he would just drive there. 15 minutes later I would just see him in the room.

Ross: I think the doctors and nurses didn't completely understand why we wouldn't just stop her life support. They could see it that it was very difficult. They would talk to us at different times. One time they said we just want to talk to you without your wife. When I met with them, I told them that, in this type of matter, my wife and I make decisions together, and are on the same page, so there is absolutely no point for you to meet with me separately or schedule a meeting when she's not there.

**Sophia**: It took a lot longer, way longer than anyone could have expected. And I think they did see that it was difficult, and I think they were respectful and trying to understand our perspective.

**Ross**: They could see that it was very hard for us to be there and they cared a lot about us. The Rabbi was helping the whole time. He said whatever decision you make, you are the parents. You don't have to follow my advice.

But this is my advice -- he did say that right now it's difficult, but later you'll look at it and you'd feel better about it that you had time to say goodbye, you had time to make peace with it.

**Sophia:** I don't feel upset at the doctors. They had the best in their heart.

**Ross:** It was important for us to do what we thought is the right thing to do. These are extremely difficult painful decisions, at some point less medical and more moral decisions. We wanted to make sure we can live with these decisions for the rest of our lives. At the end of the day we feel we did the right thing, and having that time helped us transition in the grieving process as well.

**Sophia:** I remember a nurse at some point said that if it

drags out too long, we'll have to have a hospital ethics committee talk about it. But honestly, I didn't get upset with her because I knew she cared.

Sophia: There was one doctor that was more insistent on taking out the breathing tube, especially towards the end. She actually had two siblings who died from Leigh's Disease, so she was very affected by the fact that she now was taking care of a baby with it. She really cared, but it was also upsetting for her. But after Miriam died, we got a card from her and she wrote that, "your courage and conviction as a couple and your faith were so evident". She wrote, "You touched my heart."

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## Fellow's Column

### Stranger Alexis Morvant, MD Boston, MA



As a new pediatric palliative care fellow in my first days of fellowship, I quickly appreciated that I was a stranger in a strange land, embarking on a journey to a place of new attitudes, language, and traditions. During fellowship I unquestionably endured growing pains as I attended to my culture shock and stretched to view medicine through a new and unusual lens.

From acquiescing to seemingly endless silent pauses to accepting its prolific world of grey, as a new fellow I soon realized that palliative care is a field of medicine where creative approaches to patient care, staying

nimble, and precise language meld into something strangely wonderful. In my new culture, I learned about the compelling attitudes, intentional language, and empathic traditions which are pervasive aspects of pediatric palliative care.

Attitudes. Prior to fellowship, there was plenty I thought I knew about what was right or what was wrong in medicine. I now realize how simplified that black and white world, and its solutions, were. Instead I found myself dumped in a proliferating world of grey, lacking bright and shiny answers or easy algorithms for navigation. Palliative care challenges us to learn how to gain the confidence necessary to be comfortable with "gliding in the grey with grace," says Dr. Rick Goldstein. As a fellow, yielding to this world of grey, I quickly realized the answer is almost always, "it depends" or "tell me more." What once were simple facts to me pre-fellowship are now transformed into subtlety and nuance. And that's okay. In fact, it can be quite beautiful.

Language. In my first months as a traveler to the world of palliative care, I also learned the importance of language. To those who practice palliative care well, words are compared to a surgeon's scalpel, requiring great skill to achieve desired results and tremendous presence in the moment. Being tasked with choosing the words

necessary to engage a family on their worst days requires precision and intentionality. For the first two weeks of fellowship, I avoided speaking out loud to families, terrified I would choose the wrong words and make someone's worst day...well, even worse. In time, I gained confidence and developed a voice that was still mine but new and more reflective. My new voice is inquisitive to learn more about my patient's stories and also is comfortable with silence. I no longer reflexively attempt to answer every question asked of me. I learned to recognize how to draw the answers from families with the right questions. I learned new tolerance for the fact that many questions simply do not have answers, and that many statements just simply need to be held. I learned to attend to the emotion and not simply the words. This transition was painful at times, but it was also refreshing to know it was okay not to have all the answers.

Medicine is complex and it takes years to understand how to navigate its challenging language. I remember as a resident casually spitting out a description about a baby living her first months in the NICU as an "Ex 25 weeker with BPD now trach/vent dependent, gastroschisis s/p repair, IVH..." and so it goes. I now realize families hear and feel us as we crumble their children down into mere systems and concise phrases about the problems they experience. I recognize the need to evaluate things objectively, but I see that objectifying is a -personalization. A mother once told me, "The language physicians choose to describe patients tells me every day exactly how they actually feel about and see my son. They mostly see him as a dysfunctional liver. He is much more than that to us."

I am re-learning the medicine that I aspired to as a premedical student. Back before I condensed patients down into systems without being cognizant of their stories of how they got here. Back before the psychosocial aspect of my note read, "family appropriate." I know these families differently now. I feel their joy and ounces of their pain sometimes. Their stories and names and smiles resonate in my brain more so than the numbers of the arterial blood gas, white blood cell count, or the ventilator settings. These numbers which once consumed me in residency now are a mere smattering of information as I try to understand and preserve a patient's story in my role as a palliative care fellow.

*Tradition.* It had been my experience that agendas and how fast we checked off our "to-do" lists set good resi-

dents apart from great residents. I loved list-making in residency and enjoyed the moment of checking off the empty boxes with such satisfaction. Attendings assessed our efficiency and abilities to know what the agenda should be for our patients. To be totally transparent, I thought the purpose of fellowship was to learn complex communication skills in order to convince families not to pursue intensive interventions. I have learned that palliative care is guite the contrary. One of the first learning objectives in palliative care fellowship is our tradition of removing the agendas of others before we engage. We are an agenda-less team. We never march into a family's space to change minds. We get to know families by listening to their beautiful stories. We assess a family's goals of care and advocate for goalconcordant care. I now embrace a big picture approach and think about how decisions in this moment may affect a family's bereavement for the rest of their lives. Once we are able to delineate goals of care for a family, we are better able to preserve the narrative the family believes to be most important according to their agenda. I have learned to look with care at my agenda.

In residency we are expected to know our patients inside and out, using a lexicon of systems and numbers. Traditionally, young physicians are encouraged to understand the granular level of medicine in order to develop the skills necessary to appreciate the big picture. This big picture allows us a glimpse into the whole patient. I learned that at times the granular medicine can distract me from who my patients actually are and what is happening in the moment. Once I was able to understand granular medicine in a context that appreciated the whole person, I suddenly noticed my patients' stories with much greater detail and feeling than I had ever previously experienced. I found myself reckoning with the raw, sad, beautiful human experiences around me. Patient stories can consume young fellows as we transition into our palliative care roles (and somewhat new identities). These profound initial experiences are lasting reminders of the importance of developing resiliency, self-care, and coping strategies.

My palliative care fellowship provided me with the opportunity to develop the resiliency and humility necessary to sit with the silent greyness that is present when invited into the beautiful world of patients living with serious illness. Yes, entering this culture comes with plenty of growing pains. But this strange land is exactly where I want to be. I feel less and less like a stranger with each new day, making this journey totally worth it.

## Ask the AAP President-elect Candidates:

The 2018 National AAP Election for president-elect and district officers begins Friday, November 2, 2018 and will at noon central time on Sunday, December 2, 2018. From now until then, the candidates answer questions that are then shared with the appropriate groups.

Sally Goza and George Phillips, our President-elect candidates, were posed the question: "How can the AAP foster diversity across the section of the AAP?". Please find their responses below.

#### From Dr George Phillips



Many of us are engaged with the AAP because someone asked us to participate. We are fortunate to have experienced the value of that invitation. As AAP members, the first step we can take to foster diversity and inclusion is to invite a colleague who adds diversity to join our work in the AAP. I know that together we can help newly-

engaged members find a home among our excellent Sections!

I would ask Sections to specifically invite medical students by creating programming for pediatric interest groups that exist at most medical schools. Developing programming that addresses diversity can deliver greater value in AAP membership for current and future Section members.

I would also ask Sections to create content our members can use to encourage a more diverse representation of their patients to consider careers in healthcare. Over time, as we create a more diverse pediatric workforce, I am confident that the pediatricians among them will join the AAP, and its Sections, because of the inclusivity demonstrated to them at such a formative stage.

We know that a more diverse healthcare team delivers better care, and a more diverse AAP will provide stronger advocacy and education. The AAP Task Forces on Diversity and Inclusion and Addressing Bias and Discrimination have started the work needed to promote greater diversity throughout the organization. As AAP President, I would welcome the chance to join with you to carry these efforts forward toward an Academy whose diversity mirrors that of the patients we serve.

#### From Dr Sally Goza



The richness of our AAP is in the diversity of our members and our collective voice is stronger for this. To foster diversity in all its forms across our sections we must be committed, explicit, intentional, collaborative, and visible in our efforts. Diversity alone, however is not enough. We must also focus our efforts on the "inclusion" of diverse

members. It has been said that encouraging diversity is like being invited to the party, but encouraging inclusion is like being asked to dance. We must embrace inclusion to create environments that allow all members to function at their highest potential without minimizing their diversity.

As president I would encourage that we expand our mentorship programs to explicitly and intentionally include our underrepresented member groups. We need to identify members from diverse backgrounds and ask them to be involved as mentors and mentees.

I would also want to increase the visibility of member leaders that are from diverse backgrounds. We need our leadership to be intentional in identifying and asking members from underrepresented groups to represent us when the opportunity arises.

As an AAP leader, I would actively support younger and diverse members in their careers and leadership roles; ensure that all our member leaders are mutually respectful; seek out the opinions of others and provide opportunities for our diverse membership to speak out on the issues they are passionate about; and work with our members and staff in the AAP to enable the contributions of all.

# **Upcoming Events**



November 2-6, 2018 in Orlando, FL

**AAP National Conference & Exhibition** 

November 5-7, 2018 in New Orleans, LA

National Hospice and Palliative care Organization (NHPCO) Interdisciplinary Conference

April 15-17, 2019 in Washington DC

National Hospice & Palliative Care Organization
Management & Leadership Conference

April 28 - May 3, 201 in Boston, MA

Palliative Care Education and Practice (PCEP)



Please send your comments about these articles to the LISTSERV® at PPCAAP@LISTSERV.AAP.ORG!

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#### **Submissions:**

All section members are invited to send articles or suggestions to Katie Bucklen, the newsletter co-editor.

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