Summary – Palliative Care & Hospice

Dr. Pat O'Malley

Although many people have heard of hospice, many people have not heard the term palliative care before--and if they have they usually have an image of something like an angel of death, wearing a long black robe, carrying a sickle and an hourglass. In fact, to my way of thinking, hospice in the United States is best thought of as an insurance benefit, and palliative care is really about living, not dying. But let's examine some official definitions.

Here is an official definition of palliative care, from ChIPPs, the Children's International project on Palliative/Hospice Services.

Palliative care is the science and art of lessening physical, psychosocial, emotional, and existential suffering.

Dr. O'Malley shares that she personally finds that still a little gloomy, and is working on a marketing makeover for palliative care, which acknowledges the suffering but focuses on augmenting comfort, joy, autonomy, safety, and meaning. However, she will confess it is sometimes a hard sell, both to clinicians and to families. We might all subscribe to the goals of living long and living well, and palliative care is usually introduced when hopes for one or both of those goals are challenged. But we can still hope to live as long and as well as possible. Palliative care is appropriate for any child or person facing a lifespan limiting condition. At its best, it should be putting all our medical knowledge and technology to the service of enhancing our patients' comfort, joy, autonomy, safety, and meaning. So, I think it is not about dying, but rather about living, and Dr. O'Malley thinks it should begin in utero!

<u>There are at least three implications to this definition:</u>
First, that it is inherently a multidisciplinary endeavor, with a team concept, that starts with the family as the unit of care, and the family as the pilot of the plane, and may include as navigators the MDs, RNs, child life, chaplaincy, social work, psychology, pharmacy, dietary, in fact any specialty that has an impact on the individual's quality of life.

Second, that palliative care is guided by the goals of the child or adult patient and their family. Those goals might include:

- Cure of disease
- Avoidance of premature death
- Prolongation of life
- Maintenance or improvement in function
- Relief of suffering
- Enhancing quality of life
- Maintaining patient autonomy
- Achieving a good death

- Survivor care: support for families and loved ones
- Partnering with patient and family to make the best decisions

So, a palliative care approach can benefit patients and families whether the overall goals of care are to cure, prolong life, maximize quality of life, or ease the pain of bereavement, and can be concurrent with or as an alternative to curative care. Whenever someone has faced a serious illness, or a change in health status, their goals may shift, and things may get reprioritized. This is to be expected in the life of any child or adult with a chronic illness, and it is helpful to think through these goals explicitly whenever there is a change in health or function status, in the setting of the care, or in treatment preferences.

From healthy to ill or from ill to healthy, from home to hospital and back again, wanting to consider that multivisceral transplant or deciding to forego it, are all events that call for re-examination of goals. And this examination and review must take place in the setting of ambiguities-how often we cannot clearly predict a course of a condition, and how often we cannot clearly predict the impact/benefit/ or burden of a proposed treatment. These ambiguities can make it terrifically hard to get our bearings and make teamwork and partnering with families essential. Palliative care doesn't always clarify those ambiguities, but can keep families company while walking in the dark. We can also keep families company and share in the burden of decision-making in these very ambiguous settings that are typical of chronic disease care, especially mitochondrial disease, knowing that we can only make the best decision we can with the information we have at the time, and there is no crystal ball.

Finally, palliative care takes the ability to reframe. Dr. O'Malley points out this as an area where she learns from her families all the time. For example, one family whose child is only intermittently able to take food by mouth wanted to make sure that he was still part of the family meal time. When all he could take was ice chips by mouth, they would freeze up different imaginary food shapes and let him pick whether she was having ice chip roast beef, or ice chip chocolate cake. Sometimes this reframing is important for the entire team, as when a family decides to limit potentially life extending treatments like breathing on a respirator, they might feel, or their clinicians might feel that they are deciding to "let the child die." In reality, they may be deciding to let the child live, with as much meaning and comfort as possible, and as free as possible from burdensome technology that extends but does not affirm their child's life.

So now a word about hospice. Dr. O'Malley lightheartedly describes the image of hospice that some may remember which features a nun in a white cowl leaning over the bedside of a dying patient. And indeed much compassionate care is given to patients on hospice. But it is much more practical to think of hospice as a **Medicare reimbursement benefit for patients with limited life expectancy who agree to forego the goal of cure.** Forget the nuns in white cowls.

Hospice benefits under Medicare

- Limited life expectancy (under 6 months)
- Patient elects hospice rather than standard Medicare benefit
- Palliation rather than cure
- Care provided by a Medicare-certified agency
- Physician directs care of team
- Available/able/willing caregiver at home (this is often a real challenge)
- Relies on a defined "prognosis" (read this as "time left to live")
- No longer sees prolongation of life as a goal
- Must be easily accommodated in home setting
- Can not have expensive or intensive care needs

This model was derived from adult cancer patients, who often come to a point in their cure-directed treatment when cure is no longer possible, and when the days they have left become pretty predictable. So not always compatible with adult needs, and rarely compatible with pediatric needs, unless all those criteria are met-for instance, it works best for children who are dying of cancer, precisely because that population of children most closely matches the adult model.

In Massachusetts where MitoAction is based, the recent health care reform resulted in the PPC program

- State funded pedi pallcare consultation "PPC"
- Provided by regional hospice agencies
- Eligibility is any child with lifespan limiting condition not insurance based, paid through DPH
- Does not preclude home-based nursing benefit

Some but not all patients under palliative care will end up on hospice. Hospice care is one part of palliative care, but by no means the biggest part!

- **How does one know when a child/patient is hospice-ready? Does this mean that there is an agreement "not to treat?" Do medications or supplements stop if the patient is part of hospice/palliative care?**

First let's begin by trying to make a clear distinction between palliative care and hospice care. So, in the case of being hospice-ready, yes, there may be a philosophy to limit treatments. Perhaps the best way to understand it is that there is an expectation that the cost of the patient's care will fit within the slender budget of hospice, so return to the hospital will mean that a patient is discharged from hospice, use of expensive treatments that will no longer cure, but may reduce symptoms, like radiation, or giving blood products may have to be negotiated with one's insurance agency and covered as a separate carve-out. There is some fine print wiggle room, and in fact once signed up for hospice if you change your mind, you are simply discharged from hospice-with some red tape and paperwork, but thinking about hospice as a medical insurance health benefit is the best context that I have found to understand the ins and outs. When a patient of any age is actively dying, hospice care is simply wonderful.

To be palliative care-ready, however, a child or adult needs simply to be facing a life-span limiting condition, with no implication that they are foregoing any treatment, but simply acknowledging that there may very well be very difficult decisions that will surface over the course of dealing with that condition. The American Academy of Pediatrics, for instance, supports thinking about pediatric palliative care very differently. With an entrance criterion as simple as a child who is not expected to live to adulthood. AAP supports involvement of palliative care from time of diagnosis of a life threatening or lifespan limiting condition

- **Is hospice or palliative care only appropriate when the patient is failing? In mitochondrial disease, patients often have remarkable comebacks after periods of terrible regression. What would you suggest in this case**

This is a pattern of disease and health which is so much more common in pediatric palliative care than in adult palliative care-a child whose lifespan we know is likely to be shorter than the average bear, who faces true life-threatening crises in their health, but also has the potential to come back to what is for them their normal life, or to come back with some additional burdens of treatment or limitations of function. This is precisely the sort of situation where palliative care can be helpful.

- **Does participation in palliative care positively or negatively impact other doctor's and caregivers perception of how to treat the patient? Parents are concerned it implies that the family has**

Realistically, yes, patients can get "dinged" for adding a palliative care specialist to their team. Dr. O'Malley has experienced a change once there is a pallcare note in the patient's record, and the family may find staff asking them if something has changed, if their child or patient is now DNR (the terminology used to describe choices to limit life-extending treatments), etc. However, increasingly clinicians are understanding that palliative care operates as a kind of interpreter, interpreting families hopes, fears, values, and goals to clinicians, and interpreting choices and recommendations by clinicians to the family. This is a valuable service for both sides. And often clinicians are not comfortable naming the things that families most fear-the "what ifs" that it is helpful to talk about to help families prepare, because they may fear that families think they are giving up on the patient. So palliative care can help create a space where conversation about these most difficult and painful, but critically important things can be discussed, without anyone feeling that they are giving up, just making good plans that hopefully they will not need any time soon.

- **Can a patient be part of palliative care for a long period of time? How does that work? Are there advantages or disadvantages to that approach? Would a patient participate or "join" while stable but with an untreatable condition such as mitochondrial disease?**

Yes - Dr. O'Malley has followed some patients for years. While palliative care can often times offer recommendations for symptom management which are useful at any time, it is helpful to have the time to develop a relationship with a provider over time so that there is some mutual trust, respect, and understanding which have developed over time before any end of life decisions have to be made.

- **Mito is often not "treatable", but the symptoms are. How do you find the balance here?**

Palliative care aims to manage symptoms to optimize a person's comfort, joy, play, work, meaning, safety, and autonomy, regardless of whether the underlying condition is treatable or not.

- **If a new treatment was discovered tomorrow, would the patient in palliative care be "ineligible"?**

No. Palliative care is goal directed care, based on the wishes of the patient. When new treatments are available, a reordering of goals may be possible.

- **How on earth does one make the decision to be a part of this type of program? Where do you find information?**

Ask your local pediatric tertiary care center or University hospital if they have a palliative care service and investigate what they would say. For example, at MGHfC, Dr. O'Malley notes that any child with Mito would be welcomed into our fold, in order for palliative care to act as consultant to the primary subspecialists who follow the child, and offer support to the family and the child. For help on finding a palliative care team in the AAP network, please email Cristy

- **How can we describe palliative care in a way that feels hopeful instead of "scary" or too much about death?**

Palliative care providers help act as interpreters between families and specialists, manage troubling symptoms that may be interfering with a person's ability to play, work, sleep, eat, give and get love and joy. Palliative care can create a space for families to discuss their hopes and fears without feeling that they are giving up. They are the "what if" team! Palliative care is care that lets the patient's spirit shine through....