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Maternalism in Pediatrics:
Is it a good thing.....or a bad thing?

June 22, 2017
Nneka Sederstrom, Ph.D., MPH, MA, FCCP, FCCM, Director, Clinical Ethics
Susan Sencer, M.D. Cancer and Blood Disorders
After completing this course, you will be able to:

• Identify maternalism versus paternalism in pediatrics
• Explain how to address internal maternalistic biases
• Develop skills for improving shared decision making

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“Broadly defined, paternalism is an action performed with the intent of promoting another’s good but occurring against the other’s will or without the other’s consent.”

“In medicine, it refers to acts of authority by the physician in directing care and distribution of resources to patients.”


Historically, paternalism implies that the physician believes that s/he ‘knows best’ and therefore has the right/responsibility to make decisions without regard to the patient’s autonomy.

Why is that so bad?

• Treatment forced against someone’s consent is a violation of the autonomy principle.
• Value justifications vary between parties – you may not value what I value
• Inability to change your mind or make new choices
• Erosion of the trust between the patient/family and the clinician

Paternalism – Is it ever good?

• Best interest standards often flirt with paternalism
• Capacity to make medical decisions – hard to allow bad decisions to be made by capacitated individuals
• Surrogates are allowed to “force” certain kinds of care on patients
  - Minor patients given treatments they may have previously refused
  - Cognitively impaired patients who retain some level of understanding to refuse care but not capacitated
  - Elderly patients who have caregivers deciding what treatment options they will be given or where they will live
Difference between the two

• To act paternalistically is to substitute one’s own judgment for that of another person and decide in place of that person for his/her best interest.

• By contrast, to act maternally is to decide for another person based on a reasonable understanding of that person’s own preferences.

• The concept of maternalism allows for a more thorough assessment of the moral justification of these types of actions. Sullivan, LL Medical maternalism: beyond paternalism and antipaternalism, J Med Ethics, 2016

• Both rest upon limiting the patient’s autonomy

Maternalism is not paternalism

• Therefore good, right?

• Maternalism –relating or pertaining to motherhood, like a mother

• Maternalism in medicine:
  - Protective
  - Shielding
  - “For your own good”
  - Overly sympathetic

Maternalism is not always benign

Case One: “Whose Kid Is This?”

• 25 week premature infant born and in the NICU
• Grade IV IVF bleed
• Mom and maternal Grandmother
  - Report from the team: “they are just so lovely and really nice people”
  - Mom says “I just can’t ever say no or let her go.”
• Month 4 develops NEC, sepsis, and kidney failure
• Month 7 still complicated, no discharge option in site, will “live” in intensive care
  - Has 8 primary nurses who grow more attached daily
  - All Attendings have cared for the child and “would love to just get her home”
  - Family “trust us” and “expects to take a healthy baby home”
• Many clinical team members refer to the child as “My Baby”

Primary Nurse On Service Recommendation

Hospital dependant child, can’t live off a vent, severe neurological deficits, multiple consistent complications, poor quality of life, parent no longer seems interested in caring a shift to comfort care and withdraw vent support/hospice
Last Week’s Attending Recommendation
Grim prognosis but more options to try, Mom not ready to let go, keep treating symptoms = continue all aggressive interventions

This Week’s Attending Recommendation
Complex case, not interested in being the “fixer”, busy service and not all that vested in this particular case = maintain the status quo till the next Attending takes over

Next Week’s Attending Recommendation
Complex case but aren’t they all, agree with comfort care and withdraw, just need more time to get Mom to make a decision = Make Mom agree with comfort care and withdraw

Whose reaction is closest to your own?
1. Primary Nurse – withdraw support now
2. Last Week’s Attending – more tx
3. This Week’s Attending – too complex/turf
4. Next Week’s Attending – make Mom Agree

Case 2: Minnesota Tiger Mom – Nothing Is Too Much
9 yr old boy with catastrophic disability
− Trached but not vent dependent at home
− Non-verbal, severe neurologic deficits
− Bed bound
− In and out of the PICU for infections – 10 times in the last 2 years with the last 4 times within 6 months
− Family is well known to the PICU – child graduated from NICU and PICU to go home with full services; part of Pulm for 9 years
− Mom was a PICU nurse who stopped working to care for child at home full time
− Latest PICU admission – worsening infection, deterioration leading to vent dependency.
− Mom is slowing down daily visits and one night comments to night nurse “It wouldn’t be so bad if he just went to sleep and didn’t wake up.”
Primary Night Nurse
Mom is tired, she feels forced to do everything, she needs a break, maybe it’s time to let him go = Start the withdraw and hospice conversation today.

PICU Attending
Multiple admissions, unable to remain healthy at home, deterioration, seems unlikely to get back to baseline, what are the goals of care = Need to discuss comfort care and withdraw at some point but maybe not this admission.

Pulmonary Consultant
We’ve done this dance before, he may perk back up, no clear indication he will be dependent forever, still have things to try, Mom can handle it = Continue aggressive interventions.

Primary Day Nurse
Mom seems distracted with other priorities, doesn’t stay/visit long, get the feeling she no longer cares = Mom is starting to abandon patient and is neglectful. We need social worker to intervene.

Whose reaction is closest to your own?
1. Primary Night Nurse: mom is tired; push for hospice.
2. PICU Attending: the child is not going to get better, but let’s not talk hospice this admit.
3. Pulmonary Consultant: he’s done this before, he’ll get better.
4. Primary Day Nurse: mom is becoming neglectful, get social worker involved to ‘straighten her out’.

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### Case 3: Expecting and Hoping for the Miracle.

- 18 year old young man with multiply relapsed leukemia, now with infection
- Family extremely religious
- As young man nears death, his mother becomes increasingly convinced that God will work a miracle
- She refuses to let staff talk with him about death and eventually to talk with him at all

### Oncology/Hospice Chaplain Reaction

Mom has faith and that will see her through, maintain my support for her wishes, try not to take her hope away

The patient has lived within this family system his whole life
Support Mom’s choice to not talk death with child

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### Primary nurse reaction

Mom is being inappropriate. I know my patient and he wants to talk, Mom should not make the doctors ignore him = Talk to the patient

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### Pain and Palliative Physician Reaction

There is no way to keep the reality from him, the pt is old enough to understand his path, we can discuss death in a way that is helpful, it’s my job to talk about these issues but I don’t want to alienate or ignore Mom = Keep talking to Mom to help her change her mind to talk with her son

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### Oncologist’s Reaction

He’s 18, he’s my patient, Mom’s voice doesn’t matter, he has the right to know = I will talk with my patient about whatever I deem appropriate

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### Whose reaction is closest to your own?

A. Chaplain: He has lived with this family all his life; this is his world. Follow Mom’s lead
B. Nurse: I know my patient. He wants to talk.
C. PPC MD: It is my job to talk about end-of-life issues, but I want to be sensitive to Mom. I feel miserable.
D. Oncologist: Forget it. He’s 18. He’s my patient, not mom. I’ll talk if I want to.
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What are your top 3 Core Values

1. Honesty
2. Compassion
3. Warmth
4. Directness
5. Intellectual Stimulation/Challenge
6. Winning/Saving
7. Make a Difference
8. Give it my all
9. Make the RIGHT Decision
10. Being Right

Managing Hope is Not Our Work

“Out poured a stream of ghostly creatures that consisted of disease, poverty, misery, sadness, death, and all the evils of the world. Pandora slammed the lid shut, but it was too late, the whole contents had escaped except for one small thing that lay at the bottom – Hope.”

Conclusion

* Our biases decide for family what their preferences are:
  - Phrases like “they are really sweet” or “my baby” assign an ownership of the clinical team on the family or child. This makes it harder to be objective about what ought to be done and not what could be done.
  - We don’t take the time to do thoughtful value assessments that are based in the reality of the situation.
  - Not helping families truly understand outcomes as early as possible does not allow for them to help us understand what they value and how that will or will not work with the child’s condition.
  - It is ok for people to decide they don’t want to continue their complex lifestyle and opt for a change:
    - Disability rights groups vs Autonomy