Risk Communication working w/ parents and pediatric patients

#### Samuel Brady, M.S. Ph.D. DABR samuel.brady@cchmc.org 07/16/19

**Conflicts of Interest: none** 







### **Communicating Benefits**

- Benefit-to-risk ratio... a physicist's perspective
- As medical physicists we do not order examinations
- BUT we should be aware of the Appropriateness Guidelines
  - Demonstrate evidence-based benefit-to-risk ratio
  - Developed by experts (both radiologists and physicists)
  - e.g., parents may come with specific questions as to why a CT was ordered instead of US



- Key to reading Appropriateness criteria
  - Based on expert panels of radiologists and physicists
  - Provides summary of
    - Differential variants and the imaging to help diagnose
    - Special imaging considerations
      - By modality
      - Sensitivity & specificity breakdown
    - Extensive reference list

Appropriateness Category Names and Definitions				
Appropriateness Category Nam	e Appropriateness Rating	Appropriateness Category Definition		
Usually Appropriate	7, 8, or 9	The imaging procedure or treatment is indicated in the specified clinical scenarios at a favorable risk- benefit ratio for patients.		
May Be Appropriate	4, 5, or 6	The imaging procedure or treatment may be indicated in the specified clinical scenarios as an alternative to imaging procedures or treatments with a more favorable risk-benefit ratio, or the risk-benefit ratio for patients is equivocal.		
May Be Appropriate (Disagreement)	5	The individual ratings are too dispersed from the panel median. The different label provides transparency regarding the panel's recommendation. "May be appropriate" is the rating category and a rating of 5 is assigned.		
Usually Not Appropriate	1, 2, or 3	The imaging procedure or treatment is unlikely to be indicated in the specified clinical scenarios, or the risk-benefit ratio for patients is likely to be unfavorable.		
Polative Padiation Level Designations				
Relative Radiation Level Designations				
Relative Radiation Level*	Adult Effective Dos Range	se Estimate	Pediatric Effective Dose Estimate Range	
0	0 mSv		0 mSv	

1.15

C\* \* . \*

Telutive Fundation Devel Designations				
Relative Radiation Level*	Adult Effective Dose Estimate Range	Pediatric Effective Dose Estimate Range		
0	0 mSv	0 mSv		
•	<0.1 mSv	<0.03 mSv		
<b>00</b>	0.1-1 mSv	0.03-0.3 mSv		
***	1-10 mSv	0.3-3 mSv		
***	10-30 mSv	3-10 mSv		
****	30-100 mSv	10-30 mSv		
*RRL assignments for some of the e as a function of a number of factors used). The RRLs for these examinati	xaminations cannot be made, because the s (eg, region of the body exposed to ioni ons are designated as "Varies".	actual patient doses in these procedures vary zing radiation, the imaging guidance that is		

American College of Radiology ACR Appropriateness Criteria<sup>®</sup> Suspected Appendicitis-Child

- Example w/ a total of 5 variants
- Demonstrates 4 imaging modalities
  - Ultrasound (US)
  - -MRI
  - CT (3-10 mSv)
  - X-ray (0.03-0.3 mSv)

Variant 2: Child. Suspected acute appendicitis, intermediate clinical risk. Initial imaging.				
Procedure	Appropriateness Category	Relative Radiation Level		
US abdomen RLQ	Usually Appropriate	0		
US abdomen	Usually Appropriate	0		
CT abdomen and pelvis with IV contrast	May Be Appropriate (Disagreement)	****		
CT abdomen and pelvis without IV contrast	May Be Appropriate (Disagreement)	****		
MRI abdomen and pelvis without and with IV contrast	May Be Appropriate (Disagreement)	0		
MRI abdomen and pelvis without IV contrast	May Be Appropriate (Disagreement)	0		
Radiography abdomen	May Be Appropriate (Disagreement)	**		
CT abdomen and pelvis without and with IV contrast	Usually Not Appropriate	****		
US pelvis	Usually Not Appropriate	0		

<u>Variant 4:</u> Child. Suspected acute appendicitis, equivocal or nondiagnostic right lower quadrant ultrasound. Next imaging study.

Procedure	Appropriateness Category	Relative Radiation Level
CT abdomen and pelvis with IV contrast	Usually Appropriate	ବବବବ
MRI abdomen and pelvis without and with IV contrast	Usually Appropriate	0
MRI abdomen and pelvis without IV contrast	Usually Appropriate	0
CT abdomen and pelvis without IV contrast	May Be Appropriate (Disagreement)	ବବବବ
US abdomen	May Be Appropriate (Disagreement)	0
US abdomen RLQ	May Be Appropriate	0
CT abdomen and pelvis without and with IV contrast	Usually Not Appropriate	****
US pelvis	Usually Not Appropriate	0
Radiography abdomen	Usually Not Appropriate	ଚତ

#### **Communicating with Providers**

"To effectively communicate risk, health care providers must understand how patients and guardians perceive risk and subsequently makes decisions. A key factor in risk perception is an individual's sense of control."\*

### **Communicating with Providers**

- Number one goal: help parents feel in control of the clinical situation
  - When physicians work with patients from the beginning they will have a greater sense of control

"[parents] should be reassured that their questions are good ones and, even when discussion is challenging, that their advocacy for the health and welfare of their children is appreciated."\*



"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel"

Maya Angelou



#### **Communicating with Providers**

"It is prudent to advocate for integration of education about radiation and medical imaging into general medical education curricula."\*

- Unfortunately, most benefit-to-risk communication occurs OUTSIDE of radiology
- Medical physicists are primary educators to radiologists... need to expand to other specialties



\*Kasraie et al. (2018). JACR, 15(5), 809-817

# **Communicating with Providers**

- Physicists/Radiologists need to team up and help educate ordering physicians on
  - What does it mean to use radiation in imaging
  - Radiation risk communication
  - Etc.
- Use hospital platforms such as Grand Rounds and other specialty conferences (e.g., nephrology)
- Image Gently® forthcoming campaign to educate medical students/residents outside of Radiology



# **Communicating with Parents/patients**

- A lot of parents are getting their medical education from
   Dr. Google
- We should *control* the source of information by developing:
  - Handouts
  - Guidebooks
  - Online resources (YouTube, etc.)
    - Describe the examination
    - Provide links to Image Gently®
    - Provide key phone numbers to contact Radiology experts



**CT** Scans

Hello, my name is Adler and I had a CT scan today. This is my mom, she stayed with me during my pictures.





Cincinnati Children's A **CT Scan** makes a picture of the inside of my body.





### **Communicating with Parents/patients**

- Most hospitals/clinics now provide (in near real-time)
  - the patient key images AND
  - radiologist's dictated reports
    - which includes CT dose reports
- Provide resources for parents to understand their child's results
  - Phone numbers and/or links to hospital/clinic websites



### Communicating with parents/patients

- Parents will still have questions in spite of all our best efforts to publish information
- As medical physicists we need to receive basic training on communication
  - Graduate programs: adopt seminars/classes
  - AAPM: provide symposia
    - PISC—white paper on communicating risk with pediatric patients and parents
  - Independent societies and universities/hospitals: provide classes



#### Communicating with parents/patients

- General course syllabus (Todd Atwood, PhD):
  - Didactic training
  - Analysis of physicist-patient interactions
  - Role playing exercises
  - Simulated patient interactions





https://vimeo.com/338954678

# A Questioning Parent

- Why is the parent questioning?
- What does the parent really need?
  - Patience & compassion from us
    - A sick child almost always raises the stress level of the parent/caregiver
    - To impart answers and knowledge about questions, we must fundamentally recognize the stress and work with it... never add to it
  - Reassurance
    - Don't promise anything you can not guarantee
      - e.g. this CT scan will not cause your child to get cancer
      - This may be your personal/profession belief/opinion... but outside of your control



#### Responding to a Question/Concern

- The science behind answering a question:
  - Listen
  - Understand
  - Respond
  - Follow up

#### Listen

- Listen to the WHOLE question... never interrupt
  - We often have preconceived ideas of how to answer a question such that we don't actually hear the question...
  - e.g., you just got a call from a technologist and a parent wants:
    - To know their child's dose
    - Are concerned with the amount of radiation used in the exam
    - Concerned that their child has already received their annual radiation limit
    - Wants to know why their child doesn't have Pb shielding too



### Understand

- Check for understanding
- Address the question with a question?
- Two strategies to employee:
  - Confirm by paraphrasing the question
  - Ask additional questions to understand the underlying concern:
    - the ROOT concern is the REAL question



#### Understand

# "I don't want my daughter to get her CT scan, I heard CT scans cans can cause cancer."

- Paraphrasing technique
  - Use synonyms

"You believe that your daughter will get cancer because of her CT scan?"



#### Understand

- Address the underlying question/concern:
  - Gently ask additional questions:

"Why do you think your daughter will get breast cancer?"

- Need to understand the parents background & bias
  - To understand their source of knowledge is to understand their concern
  - It turns out the parent was concerned because they had a history of breast cancer in their family



- We don't always need to ANSWER their question
  - We need to address it
  - We need to acknowledge it
  - We need to respond to it
- For some questions we do not have answers: "Will my child get cancer from his/her CT scan?"
  - You can not answer this question directly, BUT you can use knowledge to reassure



- How do we communicate risk?
  - Most common is to use effective dose (E)
    - *E* is limited... some have advocated to not use it since it is not patient specific
  - Traditionally, we have compared familiar risk
    - e.g., 1 in 304 Americans will die due to a car accident\*
  - Or used pseudo-epidemiological calculations to come up with mortality rates
    - e.g., 1 in 2560 may die from cancer following a [Tc-99m] MDP study\*



\*Kasraie et al. (2018). JACR, 15(5), 809-817

- How do we communicate risk?
  - Stating that only 1 in 4000 (0.025%) 10 year olds will die from a 3 mGy exposure\*
    - Is an inherently a negative statement... parents hear "die", "death", "cancer"
  - Stating that 99.98% of 10 years receiving a 3 mGy scan will experience <u>no negative effects</u>
    - Is an inherently positive statement

– Most people can not conceptualize 0.025%, but they can 99.98%

#### • How do we communicate risk?

- Other options are to communicate with out statistics or numbers\*

"Why are you recommending CT?"	"We need more information to clarify your child's diagnosis, and to direct our treatment.
	or can rapidly and accurately provide that information.
"Are there any risks of CT?"	"One concern is the possibility of cancer resulting from radiation from CT."
"How great is this risk?"	"The risk from CT is very small, if a risk at all. We are not certain that there is a risk at very low doses, like those doses in the vast majority of x-ray procedures or CT."
"How does the risk from CT compare to the	"I have considered your current situation carefully, taking into account many factors."
risk of [my child's presenting condition]?"	Depending on the circumstances:
	<ul> <li>"I have significant concern that your child has an injury or serious medical</li> </ul>
	condition. The risk of CT is at most very small by comparison, so CT is the right test to perform."
	"At the present time, your child appears to have very low risk for a serious medical
	condition. Although the potential risks from CT are very small, CT is not the best test
	at this time. If your child's condition worsens, CT might become necessary."
"When will these risks be evident?"	"The risk of missing a serious diagnosis will occur now, in the coming minutes/hours/ days. The effects from small radiation doses such as CT would take longer, even
	years, if these small risks exist."

#### \*Broder & Frush (2014). *JACR*, 11, 238-242

# Follow up

- Printed material handouts
  - As stated before, most questioners are seeking reassurance only
- Some want facts!
  - Provide documents that allow follow up from the safety of their home
  - I like to give my business card ... personal touch
    - Rarely do parents, after they have gone home and *decompressed*, call me for additional questions



#### Non-verbal Cues

- Be aware of how you project yourself
  - Don't turn your back to them while speaking
  - Always be at the same eye level
    - If they are standing, stand
    - If they are sitting, sit
  - Crossing your arms is a sign of being closed or defensive
  - Be aware of how you use your hands
    - Do not point your finger or shake it at them
  - Do not use your cell phone... give them your undivided attention



# Things to Avoid

- Don't use complex scientific jargon, unless necessary
  - You are the expert, you do not need to remind them of that by using large words and complex sentence structure
  - Prepare verbal/written responses to common questions... then you will be prepared to explain in simple terms
- Don't make a mini presentation out of your response
  - The parent's of a child in a hospital are already overwhelmed
  - Keep your comments succinct and straight forward



# Things to Avoid

- Don't get defensive
  - If the parent is agitated/angry... take a deep breath & stay calm
    - Project yourself as calm, centered, and self-assured
    - Let them finish talking, never cut across them





# Things to Avoid

- Don't get defensive
  - De-escalate the situation
    - Validate parent/patient experience... use empathetic phrases: "I can sense\_\_\_\_\_"
  - Modulate your tone of voice using reassuring, respectful, and nonjudgmental tone/words
    - Studies have shown that a parent/patient in distress will maintain an internal locus of control



### Conclusions

- Avoid the questions by being prepared:
  - Educate our colleagues in other medical fields
  - Create educational material... control the information as much as possible
  - Create consistent policies in department
    - When surveyed at CCHMC, parents/patients were confused/frustrated by inconsistent application of policies across hospital enterprise (i.e., main hospitals vs. satellite clinics)

### Conclusion

- Communicate through understanding
  - Listen, understand, respond, follow up
  - Address their ROOT concern
  - If they are frustrated, help them maintain or regain a sense of control of the situation
  - Never lie to them
    - There is a risk involved using radiation
    - Telling a parent there is no risk can discredit you in their eyes



# Thank you



samuel.brady@cchmc.org

