Engaging Patients in their Care: An Adolescent Case Study

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An Adolescent Case Study

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Acknowledgements

• Findings and analysis produced by a study funded by grant R40 MC 21522, through the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Research Program
  – Principal Investigator: Paul Darden, Oklahoma University Health Sciences Center

• Our gratitude to the adolescents, parents, and pediatric practices that allowed us to record and learn from their encounters

• The South Carolina Pediatric Practice Research Network (SCPPRN) and the Oklahoma Child Health Research Network (OCHRN)
Objectives

- Review the study of *Communication Intervention for Adolescent Immunizations*, with Oklahoma University Health Sciences Center, Dr. Paul Darden
  - Summarize impressions from **Phase 1**: *Validation of Parent and Adolescent Vaccine Awareness Surveys*
  - Report recent vaccine provider recommendations and up-to-date rates and for SC and the US
  - Reflect on emerging interpretations of **Phase 2**: Recording of Adolescent-Physician Communication and what it suggests for practice
CDC recommends that adolescents receive 1 Tdap, 1 MCV, and 3 HPV vaccines at 11-12 years of age
- 2nd MCV at 16-17 years of age

2013 National up to date (UTD) rates for teens 13-17
- MCV is 78.8% and Tdap is 86%
- HPV for females only is 38%

Many reasons why they don’t get vaccinated
- Provider visits, missed opportunities
- NIST data also cite “not needed”, “not recommended”; for HPV specifically– safety concerns, “not sexually active” and “not the appropriate age”

Purpose

• To evaluate the hesitancy of parents’ toward getting their teen vaccinated

• To identify practice-based strategies that can increase adolescent immunization
South Carolina Site

- South Carolina Pediatric Practice Research Network (SCPPRN)
  
  - 3 of 14 practices participated
- 2 urban
- 1 rural
  - Wide socioeconomic mix between practices
Oklahoma Site

- Oklahoma Child Health Research Network (OCHRN)
  - 3 Practices participated
- All urban practices
- One of which was 95%+ Hispanic
Phase 1: Modification of Opel Survey of Vaccine Hesitancy

- Revised questions Opel et al. survey of hesitancy* to be appropriate for teens & parents
  - Substituting “teen” for “child”
  - Modified language specifically to read to parent or teen
- Piloted the survey for clarity with teens and parents
- 18 items
  - Immunization behavior
  - Beliefs about vaccine safety and efficacy
  - Issues of trust in vaccines and in physician

*Opel DJ, Vaccine 2011;29:6598-605
Sampling and Chart Review

- Survey data collected on 60 teen/parent dyads in each of 6 clinics
  - Any visit
  - If 2 or more were seen, we surveyed younger sibling
- Each patient’s chart was reviewed by research staff
  - UTD for MCV and Tdap if received 1 vaccine
    - If ≥ 16 years, required receipt of MCV on/after 16th birthday
  - UTD for HPV if received 3 shots; OR if received a shot at that visit; OR if no shot due (i.e. < 4 months since HPV #2)
Methods - Evaluation

• Calculated frequency distributions
• Based on those distributions, items were re-categorized according to degree of vaccine hesitancy
• Used Fisher’s exact test to assess associations between vaccine hesitancy and teens’ UTD status
• We report parents’ survey results only because teen data did not differ from parental data
### Results

#### Table 1. Up To Date Status of Teens

<table>
<thead>
<tr>
<th>Practice Site</th>
<th>Tdap/Td</th>
<th>MCV</th>
<th>HPV</th>
</tr>
</thead>
<tbody>
<tr>
<td>All sites</td>
<td>81.8%</td>
<td>70.3%</td>
<td>43.5%</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>80.6%</td>
<td>68.4%</td>
<td>49%</td>
</tr>
<tr>
<td>South Carolina</td>
<td>83%</td>
<td>72.3%</td>
<td>37.8%</td>
</tr>
</tbody>
</table>

When all 18 survey items grouped together as a hesitancy scale, the total score was not associated with UTD rates.
## Selected Hesitancy Responses

<table>
<thead>
<tr>
<th>Survey Variable</th>
<th>Response</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you ever DELAYED a vaccine for this teen for reasons other than illness or allergy?</td>
<td>Yes</td>
<td>27</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>328</td>
<td>89.4</td>
</tr>
<tr>
<td></td>
<td>I don’t know</td>
<td>12</td>
<td>3.3</td>
</tr>
<tr>
<td>Have you ever SKIPPED a vaccine for this teen for reasons other than illness or allergy?</td>
<td>Yes</td>
<td>21</td>
<td>5.6</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>343</td>
<td>92</td>
</tr>
<tr>
<td></td>
<td>I don’t know</td>
<td>9</td>
<td>2.4</td>
</tr>
<tr>
<td>I am able to openly discuss my concerns about vaccines with my teen’s doctor.</td>
<td>Agree</td>
<td>356</td>
<td>95.2</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>14</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>4</td>
<td>1.1</td>
</tr>
<tr>
<td>All things considered, how much do you trust your teen’s doctor?</td>
<td>0-6</td>
<td>24</td>
<td>6.5</td>
</tr>
<tr>
<td></td>
<td>7-9</td>
<td>121</td>
<td>32.9</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>223</td>
<td>60.6</td>
</tr>
<tr>
<td>I trust the information I receive from my teen's doctor about vaccines.</td>
<td>Agree</td>
<td>342</td>
<td>92.4</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>17</td>
<td>4.6</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>11</td>
<td>3</td>
</tr>
</tbody>
</table>

**HPV p < .05**
### Hesitant Survey Responses

<table>
<thead>
<tr>
<th>Survey Variable</th>
<th>Response</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teens get more vaccines than are good for them.</td>
<td>Agree</td>
<td>93</td>
<td>25.1</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>157</td>
<td>42.4</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>120</td>
<td>32.4</td>
</tr>
<tr>
<td>Are you concerned that a vaccine might not prevent the disease?</td>
<td>Not concerned</td>
<td>185</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Concerned</td>
<td>147</td>
<td>39.7</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>38</td>
<td>10.3</td>
</tr>
<tr>
<td>Are you concerned that your teen might have a serious side effect from a vaccine?</td>
<td>Not concerned</td>
<td>185</td>
<td>49.9</td>
</tr>
<tr>
<td></td>
<td>Concerned</td>
<td>156</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>30</td>
<td>8.1</td>
</tr>
<tr>
<td>Are you concerned that one of the vaccines for teens might not be safe?</td>
<td>Not concerned</td>
<td>157</td>
<td>42.7</td>
</tr>
<tr>
<td></td>
<td>Concerned</td>
<td>158</td>
<td>42.9</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>53</td>
<td>14.4</td>
</tr>
<tr>
<td>I think Teens can get all of the vaccines that are due at a single visit.</td>
<td>Agree</td>
<td>87</td>
<td>23.5</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>170</td>
<td>45.8</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>114</td>
<td>30.7</td>
</tr>
<tr>
<td>Overall, how unsure about vaccines for teens would you consider yourself to be?</td>
<td>Sure</td>
<td>239</td>
<td>65.5</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>92</td>
<td>25.2</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>34</td>
<td>9.3</td>
</tr>
</tbody>
</table>
Conclusion

• The modified Opel scale for vaccine hesitancy did not predict vaccine coverage
• A surprisingly large percentage of parents did report some hesitancy about vaccines for some individual items
• Two items were associated with a lack of HPV vaccine uptake
UTD Rates in SC compared to US

SC parents recall recommendation ~30% of the time
US parents recall recommendation ~40% of the time
UTD Rates in SC compared to US Tdap

SC parents recall recommendation 50% of the time
US parents recall recommendation 57% of the time
UTD Rates in SC compared to US HPV (Female)

**Fig. 3 HPV 1st (female)**

- 2010: SC 41.5%, US 53.9%
- 2011: SC 48.7%, US 57.3%
- Trend: 1.28 (1.07, 1.53)

**Fig. 4 HPV UTD (female)**

- 2010: SC 29.5%, US 32%
- 2013: SC 40.7%, US 37.6%
- Trend: 2.29 (1.55, 3.39)

SC parents recall recommendation 65% of the time.
US parents recall recommendation 69% of the time.
UTD Rates in SC compared to US

HPV (Male)

SC parents recall recommendation 30% of the time
US parents recall recommendation 46% of the time
Conclusions

- SC continues to lag the US in Tdap and MCV UTD
- SC caught up to the US for HPV in girls
  - Still well behind for HPV coverage in boys
- Parental recall of recommendation low for Tdap and MCV
  - Likely represents a presumptive recommendation
- Recommendation higher for HPV in girls despite UTD rate
  - Recommendation even lower for boys
  - Separation of HPV from Tdap and MCV
Implications

• Both studies represent/rely on parental involvement
• The adolescent’s voice was largely silent
  – (or in the case of the survey mirrored parental responses)
• Dr. Pope will discuss ways that we can better involve the adolescent in the conversation
Statement of Purpose:
Secondary Analysis of Participation as Autonomy Promotion

Objectives: Examining recorded office visits

- Use discourse analysis of office visits to propose strategies for more effective communication

- Identify communication skills that increase more mutual information exchange, participation & autonomy

- Adapt communication for the adolescent-parent-provider triad to promote transition to adult primary care
Background: *What We Don’t Know About Adolescent-Provider Communication*

- Over 30 years of studies recording and analyzing adult patient-provider communication
- Most adolescent-provider communication studies:
  - Collect knowledge, attitudes, and content by recall
  - Rely on surveys
  - Fewer record interactions to identify specific ways of speaking and participating

Reference: Heritage & Maynard, 2006
Background: *Barriers to Promotion of Adolescent Autonomy*

- **Family- or patient-related:**
  - Decreased opportunity; Fewer adolescent visits for prevention; less family control & teen participation

- **Provider-related:**
  - Increased new information, vaccines & time demands; shift in developmental goals; perceptions

- **System-related:**
  - Fewer teens have medical home; less insurance

*Source:* NFID, 2009  
Transitional Care

• AAP (2011): The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not.

• Characteristics: developmentally appropriate, increased responsibilities, assume adult role

• Focus: Adolescents with chronic diseases, special needs, disabilities

• Less Attention to Primary Care
Setting: Exploring Communication in Adolescent - Provider Visits

- 24 providers and 120 patients from 6 practices (3 in SC; 3 in Oklahoma)
- 20 adolescent/parent dyads from each practice recorded in routine visits for immunization  (n =60)
Method: *Rating Communication in Adolescent Primary Care*

- **Framework:** The 4 Habits Communication Model (Frankel 1999) to reflect on adolescent visit contexts
  1. Invest in the beginning (rapid rapport, patient agenda, mutual plan for visit)
  2. Elicit patient perspective & respond to cues
  3. Demonstrate empathy
  4. Invest in the end, with participative education and mutual goal setting for future

Method: Discourse Analysis

- Analysis of communication practices people use when speaking with one another
- Demonstration of how specific use of language in pediatric contexts produces control, positioning, stance, expectations, exclusion, inferences, and interpretations
## Opportunities in Communication

<table>
<thead>
<tr>
<th>Exchange</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I: Jump up on the table. Good. So, you're X_____, is that what you go by?</td>
</tr>
<tr>
<td>2</td>
<td>P: Um hmm.</td>
</tr>
<tr>
<td>3</td>
<td>I: Good. Great. Well, how are you?</td>
</tr>
<tr>
<td>4</td>
<td>P: Good.</td>
</tr>
<tr>
<td>5</td>
<td>I: So, I can't give you any vaccines right now because we don't know what vaccines you've gotten. They're checking that out now, so. So, you're healthy?</td>
</tr>
<tr>
<td>6</td>
<td>P: Yes.</td>
</tr>
<tr>
<td>7</td>
<td>I: So, we'll, we'll sort that out. Take us to what she (overlap)</td>
</tr>
<tr>
<td>8</td>
<td>P2: That's fine, she was ^__^ (unclear due to overlap) for her.</td>
</tr>
<tr>
<td>9</td>
<td>I: So, looks like you saw Dr. X____ with, with cellulitis,</td>
</tr>
<tr>
<td>10</td>
<td>I: I was on vacation, right, and I sent you guys in, was that what happened? Legs, swollen...</td>
</tr>
</tbody>
</table>

48 Exchanges with Mother, with details and instructions

<table>
<thead>
<tr>
<th>Exchange</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>189</td>
<td>I: All right. So, do you have any worries or questions or concerns, at all?</td>
</tr>
<tr>
<td>190</td>
<td>P: No.</td>
</tr>
<tr>
<td>191</td>
<td>I: Okay. Good, good. All right, so, we brought up vaccines, at 13, have you had the Hep A?</td>
</tr>
<tr>
<td>192</td>
<td>P2: I have a sports form. (overlap)</td>
</tr>
</tbody>
</table>
Dr: So, how are you? You having a good summer?
Pt: Yes, Sir.
Dr: What you doing for fun?
Pt: Well, I just got back from a friend's. Should I get back up here?
Dr: Unless you want to do like a do a roving one, where you run around the room and I try to
listen to your chest while you're running. I don't, I only do that for special people, but there is a
game we can play. So, like an out of town friend? Or?
Pt: Um, well, she lives,
Mom: From her old school.
Pt: Yeah. She lives in [ ], so, I guess you could say that's out of town. (overlap)
Dr: Well, [ ] kind of out of town. That's like in the sticks. Right, she live like on a
farm kind of thing?
P: Sort of
I: Okay. Cool. Where you going to school this fall?
P: [ ]
I: What grade are you gonna be in?
P: Eighth grade.
I: Cool.
Dr: I will have to go through some of this on you, too, so, you might as well just do it all at once. How's that sound?
Child: Okay.
Dr: Please wear your bicycle helmet.
Child: Yes. **You know…**
Dr: I said it like a public service announcement.
Child: Okay.
Dr: Bicycle helmets are important. Okay. When you, when you worked in the ER like I have, it's, it's scary. I want to duct tape the bicycle helmet to my kid's head and never take it off.
Mom: I know.
Dr: Good. Good.
Child: I don't need a helmet. My cousin, I ride his bike.
Dr: Chores are good.
Mom: Um hmm.
Dr: Good for teaching responsibility. Some recent studies have shown that, actually an allowance is good thing to teach kids how to manage money. And, it's not necessarily best to be tight with chores. So, they said that an allowance is, **you know, you can** give an allowance every month and this is fairly parental preference, it's just a study that I read that was interesting. So, if you can give an allowance every week to help keep kids, it, **it teaches them** how to manage money, if they do extra chores, they can extra money, but, it's good to just always have chores and responsibilities no matter what because it teaches them that it's a family unit and that everyone is expected to pull their own weight.
Mom: Yeah.
Dr: So, chores are not necessarily tied with allowance, but, you know, allowance to teach structure and, and money management is good. So. Interesting studies, you know.
Dr.: "Well, I'm glad that you're going to a good school, and you're active in sports. The biggest risk to your age is some sort of accident like, you know, a bicycle accident or falling out of a tree accident, and as you get older, of course, car accidents become the biggest thing. And as you go through high school you're gonna see more and more people who are gonna do things that make them accident prone. And we're talking about risk-taking behavior, you know; people who drink have more accidents, people who do drugs have more accidents, so you're in charge of your health now. Your mom is still responsible for you, but you're really in charge of your health now too. So, I know you're here today, but when you come in here in the future you always have the option, you know, if there's anything serious you want to talk about, you have confidentiality and we can ask your mom to leave the room. I know it would be awkward to do it today, but certainly we could, you know, if there's something going on in your life and you need to talk to someone outside of your family, we're here for you.

Pt.: "Okay, cool."

Mom: "He is gonna start driving from Magnet to the crew with the other kids that whole we'll be more comfortable when he's gonna be driving, but now he's getting some of those things he needs to look out for?"

Dr.: "Well, definitely here's the thing, the more people in the car the more distractions there are. So, studies have shown that, you know, high school kids driving they're safer when they're by themselves than with lots of people in the car. So you've gotta stay 100 percent focused on the road because other drivers do stupid things all the time, and without any warning."

Pt.: "Okay."

Dr.: "Immunizations. We're gonna talk about a couple of immunizations today. One is the flu..."
Adolescent Specific Communication Skills

- Elicit teen & family agenda
- Integrate primary care agenda
- More open-ended questions
- Promote engagement & inclusion
- Attend to cues
- Avoid lectures
- Informed–Participatory–Shared decision making
- Increased teen responsibility & expanded role
How to make the shift to inclusive communication that promotes adolescent participation...

a) change provider habitus
b) prompt change in teen & family visit habits
For Academic Programs

- Develop transition curriculum all levels of training
- UME: Teach long-term disease survival
- GME: Care for long-term survivors & learn about transition processes
- MOC: Implement NHCTC-6 core elements
- Expand training to NP’s, PAs, others
- Include teens (esp. YSHCN) & families as experts

MISSING: Include communication skills training

References


• Harvey, K. (2013). *Investigating adolescent health communication; A corpus linguistics approach.* London, UK: Bloomsbury. [Email analysis]


