More on What We are Learning about Parents: Dyad Research from the Adolescent Health Consortium
What’s New in Clinical Preventive Services
A Focus on Parents: Formative Research from the Adolescent Health Consortium

John Santelli, MD, MPH

SAHM Annual Meeting
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March 8, 2019
Adolescent Health Consortium Project: Connecting Adolescents and Young Adults to Clinical Preventive Services

A collaboration involving:

American Academy of Pediatrics

American Academy of Family Physicians

SAHM

Society for Adolescent Health and Medicine

ACOG

The American Congress of Obstetricians and Gynecologists

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Triadic Logic Model for Improving Adolescent Receipt of Clinical Preventive Services

- Parent
- Adolescent
- Healthcare provider

Good communication
Support for confidential care

Mutual support/trust
Joint understanding

Receipt of CPS, Private time, and Confidential care

Discussion of Confidentiality
Private time with provider

Adolescent Health Training
Adolescent friendly health care environments

Health outcomes
Formative Research Design

**Focus group discussions (FGDs) in 2015 with:**

- Adolescents (16 FGDs/n=139 adolescents)
- Young adults (4 FGDs/n=32)
- Parents of AYA (4 FGDs/n=33)
- Healthcare providers (12 FGDs/n=95)

**National Internet Survey (NIS) in 2016**

- National probability survey, online panel, address-based sampling, response rate=65%
- Adolescent parent dyads (n=1209)
- Young adults (n=709)
National Internet Survey Domains

- Access to care and health insurance
- Receipt of clinical preventive services
- Attitudes towards CPS, healthcare system & providers
- Confidentiality and private time with providers
- Risk behaviors
- Access to health information
Prior Research on Parents and Adolescent Health Services and Confidentiality

- The parent "voice" is often absent in research on AYA health services
- Parents attitudes/interest: want information about adolescent health but discussions with providers not so common
- Support and concern about confidentiality (key factors: perceived role as parents and their trust in healthcare provider)
- Reporters on adolescent receipt of clinical preventive services in U.S. surveys (MEPS, NHIS, NSCH)

FGDs: Understandings of CPS and Confidential Care

- Parents strongly support CPS, private time, confidential care
- Private time and confidentiality understood as transition to independence
- Considerable confusion about the “ground rules"
FGDs: Understandings of CPS and Confidential Care

- Parents (and clinicians) want clarity in laws and policies designed to support teen healthcare
- Parents want a better understanding of the benefits of confidentiality and clear expectations for their role
- Parents forceful about their perceived rights and responsibilities
- Parents supportive of CPS, private time, and confidential care – but want to know what’s happening during private time

Catallozzi et al. In preparation
FGDs: Parents Want More Information on CPS

“I think it’d be good if the doctor and the child and the parent had just a discussion initially and the doctor would explain here’s as far as he can go and how far the parents....

But let the parent and the child know that their best health care and their best well-being is the whole purpose for why we’re having this relationship.

Let everybody know they’re on the same page…”

Parent of 18-26 year old
Parent and Adolescent Attitudes Towards Preventive Care and Confidentiality

Xiaoyu Song, Dr.P.H.\textsuperscript{a,b}, Jonathan D. Klein, M.D., M.P.H.\textsuperscript{c,d,*}, Hanying Yan, M.S.\textsuperscript{c}, Marina Catallozzi, M.D., M.S.C.E.\textsuperscript{f,g}, Xianling Wang, M.S.\textsuperscript{c}, Jenifer Heitel, M.P.H.\textsuperscript{f}, Kristen Kaseeska, M.P.H.\textsuperscript{d}, Julie Gorzkowski, M.S.W.\textsuperscript{d}, and John S. Santelli, M.D., M.P.H.\textsuperscript{f,g}

Confidentiality Discussions and Private Time With a Health-Care Provider for Youth, United States, 2016

Stephanie A. Grilo, M.A., M.Phil.\textsuperscript{a,*}, Marina Catallozzi, M.D., M.S.C.E.\textsuperscript{b,c,d}, John S. Santelli, M.D., M.P.H.\textsuperscript{b}, Hanying Yan, M.P.H.\textsuperscript{c}, Xiaoyu Song, Dr.P.H.\textsuperscript{f,g}, Jennifer Heitel, M.P.H.\textsuperscript{b}, Kristen Kaseeska, M.P.H.\textsuperscript{b}, Julie Gorzkowski, M.S.W.\textsuperscript{b}, Alexandra E. Dereix, M.P.H.\textsuperscript{b}, and Jonathan D. Klein, M.D., M.P.H.\textsuperscript{f}

Discussion of Potentially Sensitive Topics With Young People

John S. Santelli, Jonathan D. Klein, Xiaoyu Song, Jennifer Heitel, Stephanie Grilo, Mengru Wang, Hanying Yan, Kristen Kaseeska, Julie Gorzkowski, Madeline Schneider, Alexandra E. Dereix and Marina Catallozzi
Adolescents and parents often agree about the importance of preventive services, private time and confidentiality.

Parents value clinical preventive services somewhat more than youth.

Youth value confidentiality somewhat more than parents.

Both parents and adolescents think private conversations should start later (mode=age 18) than recommended guidelines (age 13).

**Age at which parents and adolescents think private time should begin**

*Song et al. 2019*
How important is it that adolescents and young adults have preventive visits?

- **13-14 yo parents**
  - Refused: 5%
  - Very unimportant: 10%
  - Somewhat unimportant: 20%
  - Somewhat important: 30%
  - Very important: 40%

- **13-14 yo adolescents**
  - Refused: 5%
  - Very unimportant: 10%
  - Somewhat unimportant: 20%
  - Somewhat important: 30%
  - Very important: 40%

- **15-18 yo parents**
  - Refused: 5%
  - Very unimportant: 10%
  - Somewhat unimportant: 20%
  - Somewhat important: 30%
  - Very important: 40%

- **15-18 yo adolescents**
  - Refused: 5%
  - Very unimportant: 10%
  - Somewhat unimportant: 20%
  - Somewhat important: 30%
  - Very important: 40%
During a preventive visit, how important is it that a health care provider talks about:

Mental health and emotional issues (e.g. stress, anxiety)?

Female adolescents and parents

13-14 yo parents
- Very unimportant: 5%
- Somewhat unimportant: 10%
- Neither important nor unimportant: 5%
- Somewhat important: 25%
- Very important: 55%

13-14 yo adolescents
- Very unimportant: 5%
- Somewhat unimportant: 10%
- Neither important nor unimportant: 5%
- Somewhat important: 25%
- Very important: 55%

15-18 yo parents
- Very unimportant: 0%
- Somewhat unimportant: 0%
- Neither important nor unimportant: 5%
- Somewhat important: 40%
- Very important: 55%

15-18 yo adolescents
- Very unimportant: 0%
- Somewhat unimportant: 0%
- Neither important nor unimportant: 5%
- Somewhat important: 40%
- Very important: 55%
During a preventive visit, how important is it that a health care provider talks about:

- **STIs and HIV?**

**Female adolescents and parents**

- **13-14 yo parents**
  - Very unimportant: 15%
  - Somewhat unimportant: 30%
  - Neither important nor unimportant: 15%
  - Somewhat important: 15%
  - Very important: 35%

- **13-14 yo adolescents**
  - Very unimportant: 15%
  - Somewhat unimportant: 30%
  - Neither important nor unimportant: 15%
  - Somewhat important: 15%
  - Very important: 35%

- **15-18 yo parents**
  - Very unimportant: 15%
  - Somewhat unimportant: 30%
  - Neither important nor unimportant: 15%
  - Somewhat important: 15%
  - Very important: 35%

- **15-18 yo adolescents**
  - Very unimportant: 15%
  - Somewhat unimportant: 30%
  - Neither important nor unimportant: 15%
  - Somewhat important: 15%
  - Very important: 35%
Ever had Private Time and Ever Discussed Confidentiality

### Adolescents

<table>
<thead>
<tr>
<th></th>
<th>Females</th>
<th>Males</th>
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<tbody>
<tr>
<td>Ever Discussed Confidentiality</td>
<td>42%</td>
<td>33%</td>
</tr>
<tr>
<td>Ever Had a Private Visit</td>
<td>35%</td>
<td>32%</td>
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</tbody>
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### Young Adults

<table>
<thead>
<tr>
<th></th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever Discussed Confidentiality</td>
<td>60%</td>
<td>48%</td>
</tr>
<tr>
<td>Ever Had a Private Visit</td>
<td>71%</td>
<td>60%</td>
</tr>
</tbody>
</table>

Grilo et al. 2019
Kinds of healthcare that minor adolescents should be able to receive confidentially, without their parents’ permission:

- Go to their regular health care provider
- Go to an STI clinic
- Get treatment for an injury or assault
- Get a vaccination
- Get emergency contraception
- Have an abortion
- Receive counseling for drug or alcohol use

15-18 yo females:

- No
- Don't Know
- Yes

Parents of 15-18 yo females:

- No
- Don't Know
- Yes
Parent was in the room during last visit to provider
Parental Involvement in Young Adult Health

Many young adults reported continued parental involvement in accessing health care (19-22 & 23-26 years):

- Remaining on parents’ health insurance (65% & 33%)
- Parents helping to schedule appointments (32% & 12%)
- Parents attending office visits (32% & 12%)
- Parents accessing information/results from visits (33% & 16%)
Summary: Parents Perspectives

- Support preventive care, private time and confidentiality for their adolescents
- Parent and adolescent attitudes often very similar
- Parents conflicted over confidentiality and private time
- Want clear guidance on laws and office practice, particularly for private time and confidentiality
- Support private time but want to know what happened!
- Remain involved in facilitating healthcare for young adults
- Strong protective impulse remains
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To what extent do you agree or disagree with the following statements about your adolescent seeing his/her health care provider:

**Parents**
- I prefer to be there for support and advice.
- Having private conversations could encourage my adolescent to take responsibility for their health.
- It's important that I be present for my adolescent's protection.
- If I were present, I might want to change the outcome or discussion.

**15-18 yo adolescents**
- I prefer my parent to be there for support and advice.
- Having private, one-on-one conversations could encourage me to take responsibility for my health.
- It's important that my parent be present for my protection.
- If my parent were present, they might want to change the outcome or discussion.
Summary: Adolescents and Young Adults Perspectives

- Value discussions with their provider, but also value alternate sources for health information
- Want to know what to expect at preventive visits
- Younger adolescents expressed anxiety about receiving care without parental involvement

Ever having had a talk about confidentiality and ever experiencing private time are:

- Important facilitators of AYA-provider communication
- BUT only a third of adolescents and two thirds of young adults have experienced these!
Summary: Provider Perspectives

Many providers:

• Have developed strategies for preserving adolescent confidentiality and negotiating private time

• Expressed concern about the ambiguity between parent and clinician roles in adolescent care

• Identified a need for clear professional guidance regarding office practice and emphasized the role of laws and policy in provision of care to adolescents

• Experienced time constraints as a major barrier to providing preventive care