How Does the Provider-Patient Interaction Shape the Experience of Sexual Health Communication? A Qualitative Study of Adolescents and Young Adults

Taraneeh Shafii, MD, MPH1; Andrea J. Hoopes, MD1; Samantha K. Benson, MPH1; Linda K. Ko, PhD1; Diane M. Morrison, PhD1; Heather M. Buesseler, MPH2; Matthew R. Golden, MD, MPH1; King K. Holmes, MD, PhD1
1University of Washington; 2Institute for Reproductive Health, Georgetown University

Purpose: Healthcare providers are in the unique position to offer sexual health guidance to their patients; however, there is little evidence as to the most effective method of discussing sexual health with adolescents and young adults. Research in adult populations suggests that effective provider-patient communication is associated with positive health outcomes. The purpose of this study was to explore adolescent and young adult perspectives on the provider-patient interaction when discussing sexual health in order to understand what patients need and inform the development of effective communication strategies for providers when addressing sexual health.

Methods: Semi-structured, one-on-one interviews were conducted with males and females (14-19 years) seeking care in a public health Sexually Transmitted Diseases Clinic and reporting at least one episode of unprotected vaginal sex in the last two months. Interviews elicited patient perspectives of provider-patient interactions when discussing sexual health and their level of information, motivation and behavioral skills with sexual health. Transcribed interviews were uploaded to ATLAS.ti and coded independently by two investigators. Using thematic analysis, codes were explored within and across interviews, and any code discrepancies were resolved by discussion among three investigators. Codes were subsequently categorized into thematic code families to reach consensus about significant themes.

Results: Twenty-four adolescents and young adults were interviewed with 63% (15/24) female. Five major theme families emerged from the interviews: 1) Opinions and prior experiences of the provider-patient interaction. For example, wanting providers to normalize sex during discussions and preferring interactions that reinforced their autonomy in the visit, as if talking with a collaborator or “friend”; 2) Individual-level patient factors that are facilitators and/or barriers to discussing sexual health with providers. For example, fearing being judged about their sexual behavior and feeling that some information was “too personal” to discuss with providers; 3) Perceptions of the role of the provider in promoting sexual health. For example, believing that providers are a reliable source to validate health information gathered from the internet or peers; 4) Concerns about confidentiality during and after the visit; and 5) Participant inconsistencies and/or contradictions with their preferred provider-patient interaction and level of information, motivation, and behavioral skills with sexual health. For example, while expressing their desire for empathic, non-judgmental provider communication, participants also proposed harsh rebukes, threats, and the use of “scare tactics” to discourage other young people from risky sexual behaviors.

Conclusions: Using their own words and descriptions, this study demonstrates how various themes shape the adolescent and young adult experience when discussing sexual health with providers. Participants desired sexual health information from providers, but only if it was specific to their individual needs. These data identify issues important to adolescent and young adults to help develop effective communication strategies for providers who discuss sexual health with their patients.

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“It’s Just Always Been Like That”: A Deeper Understanding of Social Context and Adolescent Bullying

Carla T. Hilario, MSN¹; Emily K. Jenkins, MPH¹; Cara Ng, MA¹; Rebecca J. Haines-Saah, PhD¹; Joy L. Johnson, PhD, RN²

¹University of British Columbia; ²UBC/Canadian Institutes of Health Research (CIHR)

Purpose: Despite ongoing anti-bullying efforts, teen bullying continues to persist and remains a significant challenge. Anti-bullying campaigns have tended to focus on changing individual behavior at an interpersonal level. However, such approaches fail to account for the ways in which bullying is taken up and enacted in young peoples’ day-to-day lives within particular contexts. The purpose of this study was to gain a deeper understanding of the range of narratives young people use to describe their experiences and perceptions about bullying, with the goal of informing more effective public health approaches that account for the psychological, interpersonal and contextual dimensions of bullying behavior.

Methods: We used a narrative inquiry approach to analyze 27 interviews with 14 girls and 13 boys aged 14 to 18 years living in a rural community in British Columbia, Canada. Interviews focused on generating rich stories of youth’s perceptions and experiences with bullying. Interviews were audio-recorded and transcribed. NVIVO qualitative software was used to facilitate coding and analysis. Transcripts were analyzed for the ways that young people tell stories about their experiences and understandings of bullying.

Results: Several prominent narratives about bullying were identified within the interviews: denial, bullying as ‘normal’ and at times justified, and bullying as fueled by notions of ‘race’. While we were aware that bullying was a significant issue in this community, some youth maintained that bullying was not occurring or that they “don’t really see it”. For many youth, bullying was perceived as a ‘normal’ part of growing up and often framed as widespread and inevitable because “it’s just always been like that”. These narratives highlight the hopelessness youth have experienced in dealing with experiences of bullying and how “nothing stops it”. Other stories framed bullying as justified and as a mechanism for righting a wrong. In this way, bullying was seen as self-defense and acts of aggression as ‘deserved’. One young woman recalled an incident in which she was being teased and ‘made fun of’ by another girl and in retaliation she “threatened to cut her throat.” Lastly, a powerful set of stories linked instances of bullying to highly racialized social divisions. When asked about bullying and social context, many young people shared stories about racism and the social as well as physical drivers of ‘race’-based divisions wherein “skin color and where you live is a huge separation”. Their narratives framed experiences of bullying as shaped by long-standing dynamics between ‘Whites’ and ‘Natives’ within this community, “which isn’t a good thing, but it happens”.

Conclusions: Findings from this study contribute to understandings of the contextual nature of adolescent bullying. Adolescent health clinicians and educators need to be mindful of the different narratives that youth may use to describe their experiences of bullying. Policies and programs that are responsive to the social, historical and political factors shaping adolescent behavior within particular contexts represent an important addition to anti-bullying approaches focused solely on individual behavior.

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Arthriting – Insights About the Links Between Identity, Arthritis and Medication in the Blogs of Young People Living with Juvenile Arthritis

Nicola J. Gray, PhD, FSAHM1; Janet E. McDonagh, MBBS2; Julie Prescott, PhD3; Felicity J. Smith, PhD4; Kevin Harvey, PhD5; Karen L. Shaw, PhD2; David Terry, PhD6

1UK Association for Young People's Health; 2University of Birmingham; 3University of Bolton; 4UCL School of Pharmacy; 5University of Nottingham; 6Aston Pharmacy School

Purpose: To investigate the relationship between identity and medication use amongst adolescents with arthritis.

Methods: Young people (aged 11-15) with arthritis from the adolescent rheumatology clinics at a UK pediatric hospital wrote blogs on our ‘Arthriting’ website, specially created for the project under the guidance of young people at the hospital. These private blogs included thoughts about identity, the arthritis condition, medication and the use of health services. Qualitative data from the blogs were analysed using directed content analysis and corpus linguistic analysis. Ethical approval for the study was obtained from the Coventry & Warwickshire UK NRES Local Research Ethics Committee.

Results: Twenty-one young people and six parents contributed 187 blog entries to the project (mean number of entries was 7 per person, with a range from 1-36). Key comments about identity included a largely positive self-image, and determination to achieve their goals, whilst realising that there were some limits to their physical and emotional endurance that manifested themselves at school and in social activities. They strove for ‘normality’, like any other young person, and expressed a need to communicate with other young people with arthritis to compare their experiences with someone who would understand their life context. The condition might be hidden from other people: choices about disclosure were complex. Comments about the arthritis condition included reflections on the physical and emotional demands of the condition, and changes since diagnosis. Pain was the most common symptom mentioned, but stiffness and tiredness were also common. Mood changes were reported. Comments about medication and health services included active decision-making regarding relative benefit and harm, and the side-effects of some medication (notably methotrexate). Parents were key players in the supply and administration of medicines. Transfer of responsibility varied in individual cases.

Conclusions: This project, using blogs to help young people to create their own narratives, provided evidence to support significant links between identity, arthritis and medication. The level of use of medication seemed to mirror general acceptance of the condition. Weighing the benefits and harms of medication was important, and young people described their thoughts, decisions and actions with great clarity. Parents and friends provided a strong support to young people, but the ‘hidden’ nature of the condition for some young people meant that they thought carefully about telling people about their illness. This could lead to challenges at school. Context is everything: in order to engage with young people and their families, and to have meaningful conversations about medication, the context of that young person’s life – both in the way that they see themselves (and their condition) and relate to others – must be explored and acknowledged.

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“There is No Help Out There and if There is, It’s Really Hard to Find:” A Qualitative Study of the Healthcare Access and Concerns of Latino “Dreamers”

Marissa Raymond-Flesch, MD, MPH1; Rachel Siemons, BA2; Nadereh Pourat, PhD3; Ken Jacobs, BA2; Claire Brindis, DrPH1

1University of California, San Francisco; 2University of California Berkeley; 3University of California Los Angeles

Purpose: The Affordable Care Act (ACA) and immigration reform are two of the most widely debated domestic policies of the past decade. A 2012 immigration program -- Deferred Action for Childhood Arrivals (DACA) -- has highlighted the intersection of these policy issues. DACA allows immigrants without documentation between ages 15 and 31, who meet specific timeframe and education criteria, to apply for temporary legal status. There are an estimated 1.76 million DACA-eligible adolescents and young adults, or “Dreamers” in the U.S. While eligible for work permits and Social Security numbers, they still do not have access to Medicaid, nor are they eligible to buy private health insurance through the ACA’s Health Exchanges. This qualitative study is among the first to document the healthcare needs and experiences of the largest Dreamer population, young Latinos.

Methods: DACA-eligible Latinos, between 18 and 31 years old, were recruited from community settings in northern and southern California and participated in 9 focus groups. Thematic analysis was used to compare and contrast the Dreamers’ experiences.

Results: The Dreamers discussed significant barriers to accessing healthcare, health service gaps, and factors that protect this population. The single largest barrier to healthcare among Dreamers was limited financial resources. Dreamers reported that they must work multiple jobs to support their families and their educational goals, leaving few opportunities for healthy eating, physical activity, and stress management. Dreamers identified mental healthcare as their largest healthcare gap, with the greatest access challenges occurring during the transition between college and employment. Other healthcare gaps included: dental, vision, nutrition, vaccines, prescription drugs, and primary care.

In addition to financial barriers to healthcare, Dreamers reported limited knowledge about how to obtain and utilize health insurance, as well as limited trust in insurance and healthcare providers. Dreamers spoke about a long-standing hesitance to disclose their documentation status to healthcare providers for fear of legal censure and negative stereotyping. They reported that they would be more likely to utilize healthcare if they learned about it from trusted sources, including parents, friends, churches, and Dreamer advocacy organizations. They also suggested a variety of media resources which could most effectively disseminate information about health insurance and healthcare to this population.

While growing up with an undocumented status limited Dreamers’ access to healthcare, they also identified some protective effects of their status, including personal resilience and close family and community bonds. Dreamers also reported avoiding high risk sexual and substance related behaviors to prevent interactions with healthcare providers and the legal system for fear of deportation.
Conclusions: This is the first study to describe the barriers to healthcare and health challenges facing the Dreamer population. Major barriers to healthcare include limited financial resources and distrust in the healthcare system due to discrimination and fear of legal censure. Despite these barriers, Latino Dreamers want additional access to health services, including mental health and primary care. The Dreamers suggested using media, churches, advocacy groups, peers, and families to disseminate information about changing healthcare policies as state and federal programs reaching Dreamers evolve.

Sources of Support: Blue Shield Foundation of California
34. Accessing Healthcare: Experiences of Urban Youth
Melissa K. Miller, MD\textsuperscript{1}; Denise Dowd, MD, MPH\textsuperscript{1}; Jennifer Linebarger, MD, MPH, FSAHM\textsuperscript{1}; Sara Jahnke, PhD\textsuperscript{2}; Joi Wickcliffe, BS\textsuperscript{3}
\textsuperscript{1}Children’s Mercy Hospital; \textsuperscript{2}Center for Fire, Rescue & EMS Health Research; \textsuperscript{3}University of Kansas

**Purpose:** To explore the attitudes and beliefs about accessing general and sexual health care among urban adolescents and to identify barriers to care.

**Methods:** We recruited adolescents aged 14-18 years from urban community organizations for this focus group study. The discussion guide was based on the Theory of Planned Behavior and its constructs: attitudes, subjective norms, and perceived behavioral control. A professional moderator conducted six semi-structured, gender-specific sessions, which were audio-taped and transcribed. Three study team members read all transcripts, summarized key findings into memos, and assigned first-level codes. Memos were shared and first-level codes were grouped into categories. Each category was named with a descriptive term and definitions were formulated. Team members then independently recoded transcripts using the categories and recorded new categories as identified. Memos were shared at a second meeting and categories were clustered into themes. Each member then reread the transcripts to ensure thematic fit for all focus group content. A fourth team member reviewed the transcripts and a final summary memo to uncover possible areas of interpretive disagreement. Triangulation and consensus were used throughout to maximize reliability. Participants completed a brief, written survey assessing health behaviors, care utilization, and demographics before the sessions. Quantitative results were summarized using standard descriptive means.

**Results:** Fifty subjects participated. Mean age was 15.5 ± 1.3 years; 64% were female; 90% were Black; 53% reported previous sexual activity. Nearly one third (30%) did not use a condom at last intercourse. Many (22%) lacked a health check-up within the past 12 months and 35% of sexually active youth had never had a health visit for birth control or sexually transmitted infection (STI) testing. Overall, most youth valued the idea of a medical home. Many thought having a medical home could facilitate more efficient and accurate care. Participants were divided on whether they trusted doctors and healthcare providers. Factors contributing to mistrust included: lack of established relationship, fear of the unknown, poor communication, and perceptions of lying by the doctor. Many subjects expressed a fear of being experimented on which might include unneeded tests, physical exams, or treatments. Most participants identified their mother as an important referent for accessing both health information and care. Adolescents felt sexual healthcare was more challenging to access, compared to general healthcare. Adolescents expressed limited behavioral control in accessing care because of discomfort, fear, confidentiality concerns, and time constraints. Fear was described as a major factor influencing decisions for accessing care, mistrust in the health care system and providers, and desire for parental involvement in care.

**Conclusions:** Urban, minority youth placed value on a medical home and adult influences but many described mistrust of doctors and barriers to accessing care. These findings can inform future interventions to improve access to care and care-seeking behaviors among disadvantaged youth.

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“She Thought That the Girl Had Just Made it Up”: Primary Care Provider Perceptions of Parental Barriers to Adolescent Depression Care
Ana Radovic, MD; Heather McCauley, ScD; Gina Sucato, MD, MPH, FSAHM; Bradley Stein, MD, PhD; Elizabeth Miller, MD, PhD, FSAHM
1Children's Hospital of Pittsburgh of UPMC, University of Pittsburgh; 2RAND Corporation

Purpose: Only a third of adolescents with a major depressive episode receive care. Symptom severity, attitudes toward treatment, structural barriers to care, and quality of parent-adolescent communication contribute to whether parents seek mental health care for their child (Logan, 2001). If parents do not identify or acknowledge that depression is a problem, the adolescent is less likely to get care (Tanielan 2009, Logan 2002). Little is known about how primary care providers (PCPs) identify and approach these parental barriers. This qualitative study explored PCP attitudes and approaches to parental barriers to adolescent depression care.

Methods: We conducted qualitative interviews with 15 PCPs. Participants were recruited from a larger PCP study on treating adolescent depression conducted in a convenience sample of community pediatric offices with access to integrated behavioral health services. Interviews were audio-recorded, transcribed, and coded for key themes. Interview questions addressed parental barriers to uptake of care for depression within an integrated behavioral health system.

Results: Several key themes emerged from the interviews. PCPs thought parental barriers were more salient to accessing care than teen barriers. Parents were seen as responsible for prioritizing depression care for the teen, and without this, teens would not have the means (e.g. transportation, finances, parental social support, etc.) to obtain care. PCPs reported some parents refused to accept the diagnosis, instead telling the child, especially boys, to deal with their problems on their own – even refusing care after the PCP, in a private conversation with the parent, exhorted the importance of treatment. One PCP described, “I’ve had parents look at me straight in the eye and be like, ‘No. They’re fine. See you later.’” PCPs described some parents who had difficulty identifying the presence of depressive symptoms and others who would attribute symptoms to normal adolescence or a situation such as a divorce. Some PCPs expressed frustration at parental skepticism about treatment. Other barriers identified by PCPs included parental inability to access care due to work requirements, lack of support, feeling overwhelmed, or having “chaotic” home situations including family discord or violence. PCPs often equated structural barriers like transportation with a parent not prioritizing care. PCPs contrasted this with examples of good family support they believed would enable adolescents to attend follow-up appointments and have a “life coach” at home who could help with monitoring for side effects and watching for increased suicidality when starting antidepressants.

Conclusions: PCPs working in an environment with integrated behavioral health services reported that when adolescents do not access care it is often due to parental barriers. PCPs commonly noted attitudinal barriers such as not accepting the diagnosis and attributing symptoms to part of normal adolescent development as well as skepticism about treatment. PCPs believe these negative attitudes may also explain purported underlying structural barriers. Interventions which assist PCPs in eliciting and addressing parental barriers are needed to improve the uptake of adolescent depression care.

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The Role of Community Nurture in Adolescent Interest in College Attendance
David Matarrita-Cascante, PhD1; Mike Edwards, PhD2; Corliss Wilson Outley, PhD1; Heather R. Clark, MS3; Yiju Wu, MEd1
1Texas A&M University; 2North Carolina State University; 3Texas A&M Health Science Center

Purpose: In January 2010, the Department of State Health Services (DSHS) began the Texas Healthy Adolescent Initiative (THAI) in six communities across Texas. THAI is a population-based initiative to improve the overall health and well-being of Texas adolescents, and to prepare them for adult life. This study examined the project in one THAI site, the community of Harlandale in San Antonio, Texas. The Harlandale community is a low-income, predominantly Hispanic community in which attendance to college has historically not been a priority for families and adolescents. This study focused in understanding the role that the Harlandale community, particularly through their local leadership group, Familias en Acción, has played in promoting interest in attending college and admission success.

Methods: This study used a mixed-methods approach to explore the role of community in enhancing student interest in higher education and increasing the efficacy of parents to support student transition to college. Data were collected through researcher observations, analysis of site documents (e.g., monthly reports, meeting minutes, and agendas), interviews and focus groups with community stakeholders, and surveys to youth participants and parents.

Results: Familias en Acción’s greatest community impacts were facilitating parental involvement in the educational process, and strengthening community capacity, particularly among parents and youth. Through the THAI project, members of the Harlandale community, particularly parents, developed feelings of empowerment, competence, and readiness to address local issues facing youth. This was achieved, in party, through increasing parental confidence in navigating educational systems and reducing anxiety about financial and social barriers to higher education. Community impact was supported by the use of community-based participatory research approaches, a strong organizational structure, incentives for community participation, the ability to leverage existing community coalitions, and a concentrated geographic focus. Specific challenges to community impact included community conditions (e.g., poverty and gang activity) that were outside the scope of the program’s capacity, unsuccessful organizational network building, and lack of physical space to conduct programs and events.

Conclusions: The family engagement approach adopted by Familias en Acción was effective in bringing the community together around a specific youth issue in the community. By meeting the basic needs of participating families, working outside of traditional organizational networks, and building the capacity of families to support each other within the community, Familias en Acción nurtured a critical foundation to support community efforts.

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Leslie Kim Daly, MA1; Elizabeth Saewyc, PhD, RN, FSAHM1

1University of British Columbia

Purpose: Purpose: In spite of research showing that young people want their family doctors to help educate them about sexual health, clinicians are not likely to provide this type of counselling. Clinical conversations often emphasize the risks of sexual activity, and in many regards, this emphasis is well placed. However, research demonstrates that a singular focus on risks alone may not be effective in promoting sexual health. In addition, recent studies indicate that failing to address sexual pleasure in relationships may limit individuals' abilities to negotiate safer sexual practices. One first step in developing new and more effective ways to talk about sex is to ask young people what they require in clinical encounters that move beyond risk, while at the same time taking into account clinicians' perspectives.

Methods: Methods: This study employed the qualitative methods of critical ethnography. To listen to young people, while focusing on gender and social context as key concepts, we conducted individual interviews and focus groups with 48 young people between 16-19 years and with 22 sexual health clinicians in Victoria, British Columbia. The transcribed data were analyzed using a process of thematic analysis highlighting contexts and structures, including gender, that shaped young people's and clinicians' perspectives.

Results: Results: Most young people indicated they required information about birth control and protection from sexually transmitted infections. However, they also wanted to discuss positive aspects of sexual health. For example, according to one participant, clinicians “should talk about how to make sex good”. Young people requested that clinicians ask questions about orgasm, desire, sexual behaviour, and relationship issues. Young women often described concerns about physical pleasure that they never mentioned in clinical consultations. Young men and women positively described clinicians who "treat them like an equal person". Young people provided specific suggestions for clinical questions about sexual pleasure. In contrast, most clinicians highlighted their own knowledge and power, delivering content focused primarily on risk management: “this is a one time opportunity to get it into their heads that this is a big deal”. Accordingly, they tended to reserve conversations about pleasure for adult clients. Those who were preoccupied with sexual risk emphasized approaches whose goal was to control or reduce sexual behaviour, leaving little room on the clinical agenda for discussing pleasure.

Conclusions: Conclusions: Young people indicated it was important that clinicians addressed both the risks and the pleasures of sexual relationship, relating to their experiences. Clinicians had their own perspectives, often reflecting more negative attitudes about adolescent sexual health. Failing to include pleasure limited some clinicians' abilities to initiate clinical conversations relevant to young people’s wants and needs. New clinical content and new attitudes towards sexual pleasure should be developed to support young people in making healthy and responsible sexual choices.

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