SESSION I: QUALITATIVE METHODS

HOW DOES THE PROVIDER-PATIENT INTERACTION SHAPE THE EXPERIENCE OF SEXUAL HEALTH COMMUNICATION? A QUALITATIVE STUDY OF ADOLESCENTS AND YOUNG ADULTS
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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
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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 people’s 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
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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 ‘Arthiritting’ 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”
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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