

**Platform Research Presentation IV: Understanding the Role and Impact of Parent/Caregiver
Involvement and Relationships in Adolescent Health**

18.

**FAMILY FINANCIAL AND PSYCHOSOCIAL BURDEN PREDICTS POOR DISEASE OUTCOMES AMONG
MEDICALLY VULNERABLE ADOLESCENTS**

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Purpose: In the US, nearly 1-in-4 youth live with a chronic medical condition, such as Type 1 Diabetes and rheumatic diseases, and the direct and indirect costs of managing these diseases for affected families are astronomical. Despite the theoretical importance of disease burden at the family level, empirical work has yet to fully elucidate the impact of family financial and psychosocial burden on child-level health outcomes. We sought to determine how parental report of financial and psychosocial burden is associated with general and disease-specific health outcomes for their child.

Methods: Data are from 392 respondents to a national web-based survey (73.4% response rate) of parents of adolescents (ages 13-18 years) with Type 1 Diabetes (T1D, 60.5%) and rheumatic diseases (RD, 39.5%). Multivariable generalized linear regression models were used to model youth health outcomes as a function of validated measures of family financial and psychosocial burden, adjusting for confounders.

Results: Respondents were 45.8 years old on average (SD=6.2), predominantly mothers (92.1%), white non-Hispanic (91.8%), married/partnered (86.0%), and had a college degree (67.1%); their children were 15.2 years old on average (SD=1.4), predominantly female (57.9%), privately insured (79.3%), and currently taking any prescription medications (86.5%). Experience of financial burden was high: 57.4% of families spent over \$2000 on out-of-pocket health care costs in the past year, 34.4% reported problems paying medical bills in the last year, and 65.1% worried about the cost of care at least monthly. Financial burden items were strongly associated with child's general health (e.g., problems paying medical bills associated with 1.70 times the odds of their child being in worse health, 95%CI: 1.16-2.47) and disease-specific health (e.g., more frequent worrying about the cost of care associated with 1.21 times increased rate of severe hypoglycemic events, 95%CI: 1.05-1.38, and 1.42 times increase in the frequency of disease flares, 95%CI: 1.14-1.77). Psychosocial burden was also prevalent: 84.9% of parents said parenting their child with a chronic condition was more stressful than 'normal' parenting, 41.8% felt burnt out by the constant effort of managing their child's condition, and 27.0% felt alone in managing their child's condition. Psychosocial burden items were also strongly associated with child's general health (e.g., feeling burned out by constant effort associated with 1.52 times increased rate of emergency room visits, 95%CI: 1.33-1.74) and disease-specific health (e.g., feeling alone in managing child's condition associated with 0.3 unit increase in last hemoglobin A1c and 0.7 unit increase in total disease activity, both $p < 0.01$).

Conclusions: Family financial burden and psychosocial stress associated with managing a child's chronic disease both substantially impact adolescent health. Improved ability to obtain a comprehensive picture of family vulnerability will be vitally important for clinicians, public health practitioners, and policy makers who wish to apply supportive interventions to address the 'up-stream' causes of adverse health. Future work should produce strategies to identify, engage, and support vulnerable adolescents and their

families, including by developing and testing candidate measures for inclusion in a vulnerability screener.

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19.

RISK OF TRAUMA EXPOSURE AND TRAUMATIC STRESS AMONG ADOLESCENTS WITH AN OPIOID-USING PARENT

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Purpose: Adolescent offspring of adults with substance use disorders (SUD) are more likely to be exposed to trauma; youth exposed to trauma are at higher risk for substance abuse and mental health issues, including depression and PTSD. Opioid use (OUD) in particular is a dire issue; however, the impact of OUD on children of opioid users is under-studied. Given the unique risks associated with OUD (i.e., overdose), children of opioid users may endure unique experiences. The current abstract examines trauma exposure and traumatic stress among adolescents with paternal SUD and OUD.

Methods: N=114 adolescents (M(SD)age=11.82(0.59); 50% white; 30.1% female) with a biological father with and without SUD that are part of an ongoing longitudinal study were included in current analyses. We conducted structured clinical interviews (SCID-5) with a caregiver to determine paternal SUD diagnoses. Adolescents were categorized based on paternal substance use history: OUD, other SUD, and non-SUD. Adolescents completed the Screen for Adolescent Violence Exposure (SAVE) to assess traumatic experiences; caregivers completed the Child Trauma Questionnaire (CTQ) to assess trauma severity, suggestive of traumatic stress. ANOVAs and follow-up t-tests were conducted to determine differences in trauma exposure and traumatic stress symptoms across groups.

Results: Parental substance use groups were as follows: n=15 OUD, n=36 other SUD, n=63 non-SUD. Adolescents with paternal OUD reported significantly more physical/verbal abuse compared to adolescents with other paternal SUD ($t=2.20$, $p=.03$) and adolescents with no paternal SUD ($t=2.05$, $p=.04$). Adolescents in the OUD group also reported more traumatic violence compared to those in the non-SUD group ($t=2.78$, $p=.01$); there were no differences in adolescents with other paternal SUD ($p>.05$). Subsequently, caregivers of adolescents with paternal OUD also reported more severe trauma, suggestive of traumatic stress, compared to adolescents without paternal SUD ($t=3.06$, $p=.003$). Adolescents with other SUD did not significantly differ from adolescents with paternal OUD or paternal non-SUD ($p's>.05$).

Conclusions: Findings highlight the unique higher risk of exposure to physical/emotional abuse and traumatic violence among adolescents with paternal OUD as well as the high rates of posttraumatic stress symptoms among this group. This group may also be at higher risk for intergenerational transmission of violence, in addition to risk of substance use disorders and other mental health issues. Results underscore the need for mental health screening, early intervention and prevention among

adolescents who have been affected by OUD in the family. Given that many ongoing substance use issues go unnoticed, periodic mental health screening – including screening for trauma exposure – should be implemented in schools or primary care clinics.

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20.

USING LATENT CLASS ANALYSIS TO UNDERSTAND THE COMPLEX RELATIONSHIP BETWEEN CAREGIVER-ADOLESCENT RELATIONSHIPS AND MALTREATMENT

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Purpose: Approximately 900,000 adolescents are victims of maltreatment annually. Adolescents who experience maltreatment are at particular risk for negative emerging adulthood outcomes, such as homelessness, unemployment, substance use, and especially difficulty with relationships. Maltreatment can impact interpersonal relationships through disrupting an adolescent's relationship with their caregiver and may have long-term relational effects. Furthermore, interpersonal responses to caregivers following maltreatment during adolescence are complex, varied, and have developmental significance. The purpose of this study was to identify typical profiles of caregiver-adolescent relationship quality among adolescents with a history of a Child Protective Services (CPS) investigation during adolescence.

Methods: Secondary data came from the first wave of the second National Survey of Child and Adolescent Well-Being (NSCAW II), a nationally representative longitudinal cohort of children and adolescents in the United States who were subjects of child abuse and/neglect investigations in 2008-2009. Latent class analysis (LCA) with continuous and categorical indicators was conducted to identify the profiles among adolescents (ages 14-17.5 years; mean 15.5, SD 0.7) from NSCAW II (n=364). The latent construct of caregiver-adolescent relationship quality was represented by two subconstructs: 1) caregiver-adolescent relationship, which included the adolescent's feelings of relatedness, closeness, quality time, and open communication with caregiver and 2) maltreatment, which included the adolescent's reports of having serious arguments with caregiver about behavior, non-violent discipline, verbal aggression, mild physical assault, and severe/very severe physical assault in the past year. Covariates included the adolescent's age, adolescent's race/ethnicity, and adolescent's gender. All analyses were weighted to account for the complex survey design and unequal sampling probability.

Results: Four latent classes of caregiver-adolescent relationship quality were identified based on model fit statistics: positive relationship without maltreatment (39%), positive relationship with moderate maltreatment (30%), negative relationship with severe maltreatment (27%), and negative relationship without maltreatment (4%). The two classes with an overall negative relationship had similar relatedness and closeness means, but differed in the amount of quality time, where those that experienced severe maltreatment had more quality time together. The two classes with an overall positive relationship differed in the presence/absence of maltreatment, except they had similar proportions of having a serious argument about behavior.

Conclusions: Findings provide a more nuanced understanding of caregiver-adolescent relationship quality for adolescents that have been subjects of maltreatment investigations. A third of the sample reported positive caregiver-adolescent relationships despite recent maltreatment which should be explored further especially given the implications for interpersonal functioning. This study highlights the heterogeneity in this vulnerable population and underscores the need for future work to understand the type of maltreatment, placement type, and caregiver characteristics that predict membership in each class.

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21.

ASSESSMENT OF ADOLESCENT DECISION-MAKING CAPACITY FOR PHARMACIST ACCESS TO HORMONAL CONTRACEPTION

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Purpose: Multiple states allow pharmacists to prescribe combined hormonal contraception. In many cases, pharmacy access is restricted or unavailable for minors due in part to concerns about minor's decision-making capacity. Our objective was to examine adolescents' decision-making capacity for contraception after a simulated pharmacist prescribing process.

Methods: As part of a larger study of minor access to contraception in a pharmacy setting, we recruited 53 females, ages 14-21, from primary care and subspecialty clinics (neurology, rheumatology, cardiology, oversampled for contraindications). Participants underwent a simulated pharmacist prescribing process, which included completion of a self-screener for medical contraindications, providing the participant with a menu of available options based upon their screener, and method specific counseling. The simulation was followed by a validated, semi-structured capacity assessment using the MacArthur Competency Assessment Tool - Treatment (MacCAT-T). The tool assesses four components of decision-making: (1) understanding of the treatment, (2) appreciation for how the decision will affect the young person personally, (3) logical reasoning and balancing risks/benefits, and (4) making a voluntary choice. Questions are open-ended with follow-up probes to elucidate decision-making processes. Interviews are scored out of 20 using a pre-determined scoring rubric, with a higher score indicating a greater level of decision-making capacity. Predictors included demographics, health literacy (rapid assessment of adult literacy in medicine (REALM)), socioeconomic status (Family Affluence Scale II), sexual behavior, presence of a chronic illness (Children with Special Health Care Needs questionnaire). Quantitative data were analyzed using correlation, t-tests and ANOVA. Multiple regression was not done as there was not sufficient variation in the outcome. The open-ended questions were analyzed qualitatively using thematic analysis to identify key concepts related to decision-making capacity and opinions regarding contraception and pharmacy access.

Results: Of the 53 participants, 58% were from primary care clinics, 42% subspecialties; 70% were under 18 years of age; 38% African American, 36% white, 11% Latina. Participants scored high on the MacCAT-T, with little variation in the scores (18.8 (+/- 1.9)) and no correlation with any hypothesis variables. Examining differences by age below or above 18 showed no differences between sub-scores in understanding (5.5 v. 5.6), appreciation (3.9 vs. 4.0), reasoning (7.7 vs. 7.6) and choice (1.6 vs. 1.6). In bivariate analysis, neither age, ethnicity, clinic type, insurance, family affluence, sexual activity or chronic illness were statistically significant with total MacCAT-T scores. One variable found to be significantly associated was medical literacy ($p < 0.001$). Key themes included stigma around contraception use and sexual activity. Some found discussing heavy or painful menstrual cycles as a strategy for more acceptable contraceptive use—both with parents and their larger community. Participants found pharmacy access to be a convenient and discreet option. However, they did raise concerns about pharmacists' knowledge and understanding of their chronic illness. Furthermore, some participants preferred their clinical provider due to their already established relationship and knowledge of medical history.

Conclusions: Minors demonstrated high levels of decision-making capacity regarding contraception, comparable to young adults. These data support expansion of pharmacy access to hormonal contraception to adolescents of all ages.

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22.

SCHOOL/PARENTS OR OTHER PRIMARY SEX EDUCATORS: WHAT DIFFERENCE DOES IT MAKE?

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Purpose: To assess the characteristics of youths who received sex education by other means than parents or school.

Methods: 5175 young adults (51% males) aged 24-28 took part in a Swiss national study on sexual health in 2017 and were divided in 5 groups according to their answer to a question on their main sex educator during adolescence: School or parents (n=2310; 44.6%), Friends (1940; 37.5%), Internet (400; 7.7%), Other (332; 6.4%) and No sex educator (194; 3.8%). Groups were compared on socio-demographics, pregnancy and abortion, age at first sexual experiences (contact, oral, vaginal and anal), contraception and/or protection use at first sexual intercourse, lifetime emergency pill use, lifetime history of sexual transmitted infection (STI), unwanted sexual experiences (USE), sexual intercourse without really wanting, sexual abuse, sexual orientation (identity, attraction and partner(s) sex), number of lifetime sexual partners and perception of their first vaginal sex (pleasant or not). Significant variables at the bivariate level were included in a multinomial analysis using the school/parents group as reference. Results are given as relative risk ratios (RRR).

Results: At the bivariate level, groups differed for all studied variables except pregnancy and abortion, age at any first sexual experience, USE, sexual abuse and perception of their first vaginal sex. At the multivariate level, compared to the School/parents group, participants in the Friends group were more

likely to be males (RRR: 1.42), to report STI history (1.37), lifetime emergency pill use (1.16), sexual intercourse without really wanting (1.25) and higher number of lifetime sexual partners (4 or more: 1.93), and less likely to report a below average family SES (0.72). Participants who used the Internet as their main resource for sexual education were more likely to be males (2.53), to report a STI history (1.50), not using protection at first intercourse (1.72), sexual intercourse without really wanting (1.69) and a non-heterosexual orientation (1.79). Those in the group Other were only more likely to report a STI history (1.53). Finally, participants who reported No sexual educator were more likely to be males (1.66) and tended to be less Swiss-born (0.62, $p=0.055$).

Conclusions: While recommendations advocate close collaboration between home and school in terms of sexual health education, less than one participant in two reported their parents or school as their primary sex educator. Overall, those relying on friends and the Internet seem to be those taking more risks. Sexual minority youths rely mainly on the Internet, probably reflecting a sex education not always inclusive. Finally, those reporting no sex educator do not seem to be doing worse, suggesting that there are other factors than sexual education to be considered in sexual health prevention among young people.

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23.

USING BEST-WORST SCALING AND LATENT CLASS ANALYSES TO EXPLORE VARIATION IN PARENT WORRIES ABOUT HPV VACCINATION

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Purpose: Widespread vaccination against human papillomavirus (HPV) could prevent most HPV-associated cancers. Yet, uptake of HPV vaccine remains low, with only 35% of adolescents completing the series. Prior research documents the diverse worries that parents have about HPV vaccination, but little is known about the relative importance of worries or how they co-occur which could be useful to inform targeted communication campaigns. We sought to prioritize parental concerns about HPV vaccination and to assess patterns of concern.

Methods: We used best-worst scaling (BWS), a stated preference method, to prioritize parents HPV vaccination concerns. We administered the BWS instrument via a national, online survey to parents of adolescents ages 11-17 who reported never having talked with their child's healthcare provider about HPV vaccination ($n=443$). Parents completed 11 choice tasks that presented repeated subsets of 11 common worries about HPV vaccination identified in the literature. We analyzed BWS data using conditional logistic regression to prioritize parents' worries about HPV vaccination and then constructed scale-adjusted latent class logistic regression models with 1-10 classes to identify patterns of worry.

Results: Our sample was diverse in terms of race/ethnicity (63% White, 20% Hispanic, 9% Black) and included similar proportions of parents of sons (55%) and daughters (45%). Parents most often worried about long-term side effects of HPV vaccination, which about one-third (36%) ranked as their top worry. Other common top-ranked worries were how new the vaccine is (12%), motives of drug companies

(12%), short-term side effects (10%), and that it may be unnecessary (10%). In latent class analyses, the statistical fit of the model improved with each additional class (BIC: 22557 and 20962 for 1- and 10-class model, respectively). Across models, many classes were characterized by a worry about long-term side effects in combination with other worries. For example, the 5-class model suggested the following distinct parental profiles. Vaccine Harm Worriers (Class 1, 28%) were primarily concerned about long-term side effects. Industry Worriers (Class 2, 29%) prioritized concerns about drug company motives in tandem with side effects. Novelty Worriers (Class 3, 23%) were concerned about how new the vaccine is and about long-term side effects. General Risk Worriers (Class 4, 15%) were worried about encouraging sexual activity and about side effects. The smallest class, Sex Worriers (Class 5%), was characterized by concern about having to talk about sex and about encouraging sexual activity.

Conclusions: By using BWS, this study provides novel data for understanding how parents prioritize their worries, thereby informing ongoing efforts to better support parents in their decision making about HPV. Findings from this national study suggest that providers and others who promote HPV vaccination should be prepared to address concerns about long-term side effects, as this was the most frequently ranked worry and was common across classes. However, we found that parents' worries about HPV vaccination are difficult to segment into clinically meaningful groups. To best address parent worry, a tailored, rather than targeted, communication approach may be needed.

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