THE ROLE OF THE PHARMACIST IN THE SUPPORT OF YOUNG PEOPLE WITH CHRONIC ILLNESS, THROUGH THE EXEMPLAR OF JUVENILE ARTHRITIS

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Purpose: Sparse research exists about the role of the pharmacist in the care of young people with chronic illness. In a previous study by us of the experience of young people using medication to treat juvenile arthritis, references to the pharmacist were rare – and those that did occur expressed frustration with technical aspects of getting prescription refills. The role of the pharmacist has expanded in many countries over the past few years; the hospital pharmacist integrating into the clinical healthcare team at the patient bedside, and the community pharmacist offering extended medication counselling for older people with chronic illness. The aim of this project was to explore the current role, the potential role, and the needs of pharmacists to deliver services to young people using the exemplar of juvenile arthritis.

Methods: A sequential consensus-building study design was employed. Eighteen community and hospital pharmacists took part in four idea-generating focus groups across Great Britain. The thematic analysis of the verbatim transcripts from these focus groups underpinned a briefing for 15 stakeholders from the pharmacy and rheumatology community who took part in semi-structured telephone interviews. Statements of current and future roles supported by the combined thematic analysis of the verbatim focus groups and interview transcripts were presented to 13 pharmacists and 13 rheumatology staff members in three final discussion groups, where members individually - and as small multi-professional groups – rated and prioritized the ideas of the focus group pharmacists and stakeholder interviewees. In a final exercise, the pharmacists and rheumatology staff, as two separate groups, chose their ‘top 5’ current/future pharmacy activities to be prioritized in future policy and practice development.

Results: Strong themes emerged across all phases of the project. Major system-related challenges included missed opportunities to connect if parents picked up prescriptions alone, and caution among pharmacists about handing out prescriptions to unaccompanied young people. Most pharmacists felt they needed training to develop skills in communicating with young people, which was currently experience-dependent. Participants felt that hospital pharmacists should be the specialist medication contact point for their generalist community colleagues. Better information flow about young people from the hospital rheumatology setting to their nominated community pharmacy could minimize supply problems and inform minor ailment advice. Rheumatology staff also prioritized the role of community pharmacists in helping young people to develop general healthcare skills, such as navigating the prescription refill system and minimizing co-payment costs as they became young adults.

Conclusions: There was consensus both within and beyond the pharmacy profession that pharmacists could add value to the care of young people with chronic illnesses like juvenile arthritis. The roles of
hospital and community pharmacists were seen as different but complementary, with better information flow and networking across sectors required for the benefit of the young person. Community pharmacists may underestimate – and therefore not prioritize - the value of their core role of helping people to manage prescription refills and co-payments, but other healthcare providers recognize their contribution in that role.

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31.

UNDERSTANDING ADOLESCENT SOCIAL MEDIA USE: ASSOCIATION WITH SEXUAL RISK AND PARENTAL MONITORING FACTORS THAT CAN INFLUENCE PROTECTION

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Purpose: Social media (SM) is now a common venue for adolescents to explore their sexuality. Little is known about the association between frequency of SM use with adolescent sexual activity and risk behaviors, as well as the impact of parental monitoring on adolescent SM use. This study assesses 1)the association between SM use with sexual behaviors and risk and 2)parental involvement in SM use.

Methods: An anonymous self-administered survey of 13-21 year olds from three urban, primary-care clinics addressed SM use and sexual behaviors. SM use was defined as social networking sites (SNS), apps and sexting (sexually explicit texts/photos). Chi-square and regression analyses controlling for age and gender assessed associations between SM use and sexual behaviors (kissing only, fondling only, vaginal, oral, anal sex), sexual risk (>4 lifetime partners, inconsistent condom use, >1 partner in last 3 months), and self-reported STIs. Contraceptive use was stratified by gender and analyzed by type (LARC, other hormonal methods, emergency contraception) or knowledge of use by female partner. Similar analyses assessed relationships between parental involvement (access to profiles, discussion of privacy settings) and SM use.

Results: Of the 333 participants 66.3% were female, 80.2% Hispanic, mean age of 16±2 years. Frequent SNS users had greater odds of kissing (AOR 1.82;1.04-3.18), fondling (AOR 1.74;1.11-2.73), vaginal (AOR 1.93;1.13-3.30) oral (AOR 1.86;1.06-3.20), and anal sex (AOR 3.54;1.38-9.08). Frequent app users had similar patterns: kissing (AOR 2.30;1.28-3.37), fondling (AOR 2.05;1.24-3.37), vaginal (AOR 3.88;2.21-6.82), oral (AOR 1.94; 1.12-3.36) and anal sex (AOR 2.82; 1.04- 5.55). Ever sexters also had greater odds of vaginal (AOR 2.45;1.25-4.78), oral (AOR 3.54;1.78-7.04) and anal sex (AOR 4.34;1.21-15.6). Ever sexting had greater odds of more lifetime (AOR 6.61;2.60-16.76) and recent partners (AOR 3.06;1.06-8.81). SM use was associated with use of hormonal contraception (SNS AOR 1.85;1.51-2.27, app AOR 2.77;1.36-5.67, sexting AOR 3.80;1.80-8.08) and emergency contraception (SNS AOR 1.48;1.23-1.79, app AOR 1.78;1.48-2.17, sexting text AOR 1.70;1.40-2.07, sexting photo 1.73;1.42-2.10) but not STIs. Males had higher odds of sending a photo-sext (AOR 1.81;1.06-3.12). Male frequent use of SNS, apps or ever sexting was associated with being unsure of partner’s contraceptive use (SNS AOR 1.85;1.35-2.52; app
AOR 1.98; 1.41-2.80; ever sext(text) AOR 1.74; 1.28-2.38; ever sext(photo) 1.84; 1.33-2.54. 48.4% reported parental access to profiles on SNS and 45.2% on apps. 54.6% reported parental discussions of privacy settings. Females had higher odds of parental access to app profiles (1.83; 1.13-2.98) and also parental discussion of privacy settings (3.27; 2.01-5.29). Those having privacy discussions had greater odds of “private” profiles on SNS (AOR=2.61; 1.54-4.41) and apps (AOR 2.06; 1.25-3.40), and lower odds of ever sexting (AOR 0.52; 0.31-0.86).

Conclusions: Frequent SM use and sexting was associated with increase in all types of sexual behaviors; sexting alone was associated with more lifetime and recent sexual partners. Parental discussion of privacy settings was found to be protective. Providers and parents should be aware of the impact of SM use on sexual behaviors. Targeted interventions around SM use and content such as sexting need to be considered to decrease sexual risk that can lead to unplanned pregnancy and STIs.

Sources of Support: NA

32.

CHILDREN’S AT HOME: DEDICATED SOCIAL MEDIA FOR PARENTS OF ADOLESCENTS WITH NEUROFIBROMATOSIS TYPE 1

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Purpose: To evaluate Children’s at Home (C@H), a social media website created for parents of adolescents with Neurofibromatosis Type 1 (NF1)

Methods: Interventional study for parents of adolescents with NF1 aged 13-18 years including 2 phases: (1) Creating Video Intervention/Prevention Assessment (VIA) visual narratives on smartphones about parenting a child with NF1; (2) Interacting on C@H, a secure, medically-moderated social media website, with phase 1 visual narratives and responses using video and text. C@H was evaluated qualitatively via semi-structured phone interviews at: enrollment (T0), after creating video narratives (T1), and after interacting with other parents on C@H (T2).

Results: Seventeen mothers enrolled in the pilot study. At T0 – participants reported not knowing anyone else with NF1 and needing C@H to: break their isolation, connect with other families, and receive accurate information, advice, and support from others facing similar challenges. Main subjects of concern were: education, social life, current health issues, how NF1 affects family, and child’s future. At T1 (N=13, 4 dropouts due to time constraints, 145 videos over 6 months), participants reported improved awareness and quality of life from recording their visual narratives and C@H created a forum to express their feelings and fears of having a child with NF1. All parents valued sharing challenges and tips, and putting a face on NF1. Some parents reported challenges with time and with the video technology. At T2, after interacting on C@H for 7 weeks (N=10, mean 2 sign-ins/week/parent), participants reported: connecting with other parents of children with NF1 for the first time, valuing the “real faces” and emotions of other parents with shared experiences. Creating an online community removed feelings of isolation and provided a sense of normalcy. Participants reported feeling heard and...
understood, relieved to talk about NF without having to explain it, and that their lives were put into perspective. C@H addressed non-medical issues of NF1 never discussed with doctors and revealed individual versus NF1-related traits in children. Several participants reported learning more about themselves and NF1. Half reported being happy to talk more about NF1 because it brought up new issues and helped them feel better prepared to advocate, while the other half did not want NF1 to take over their lives. Parents liked best about C@H: ending isolation created by HIPAA, being part of a support group, accessing a wealth of experiential knowledge, and confidence in state-of-the-art medical oversight. What parents liked least: technological issues and being reminded that the disease was real. The majority gave suggestions for improvement, considered C@H a valuable 24/7 resource of information and strategies for living with NF1 that they would like to see continue.

**Conclusions:** Many parents of adolescents living with NF1 feel isolated in their experience. C@H allowed parents of adolescents with NF1 to connect for the first time. Innovative applications of social media dedicated to caregivers can provide peer-to-peer support, shared experience, and reliable medical information. Future research should measure the impact on the whole family.

**Sources of Support:** Children’s Tumor Foundation; Swiss National Science Foundation

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**INCREASING PATIENT PORTAL USAGE: OUTCOMES FROM THE MYCHART GENIUS PILOT PROJECT**

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**Purpose:** The Health Information Technology for Economic and Clinical Health Act (HITECH) is designed to facilitate improved the delivery of healthcare by incentivizing the implementation of electronic health records (EHR). In stage 1, health care professionals must demonstrate meaningful use by providing patients with timely online access to their health information. While adolescents are early adopters of technology, patient portal activation and use has been fraught with ethical, legal, and practical use barriers. Further, navigating the individual sign-up and download of the corresponding cell phone application is a multistep, time-consuming, and cumbersome process. The objective of study was to examine the feasibility, acceptability, and preliminary effectiveness of implementing an on-site tech-support program (MyChart Genius) to assist urban youth with EHR patient portal activation during clinical visits and to explore preferences regarding health-related technology support.

**Methods:** The MyChart Genius project was a quality improvement study staffed by tech-savvy volunteer pre-medical and medical students trained in EHR (Epic) use, patient confidentiality, and human subjects research. Staff were available during clinic sessions to assist patients in portal activation and enrollment. A MyChart Genius approached patients aged 13-25 years cared for in an urban academic Adolescent Medicine practice during clinical visits. The Genius informed the patient of MyChart portal availability,
access options, and privacy rights; requested permission to assist with portal activation, and provided instructions and support for using the smartphone application. Patients were invited to complete a brief, online survey that assessed demographics, technology access and use, communication preferences, and satisfaction with the MyChart Genius service. Geniuses tracked enrollment data and the online survey system created a data file for analysis in SPSS (SPSS Inc., Chicago, IL).

**Results:** The genius staff approached ninety-six patients and 84 (87.5%), activated their MyChart portal, and 76% of enrollees completed the online survey. Participant mean age was 18.7 (±2.3) years, most were African-American and insured by public health insurance. Respondents reported high technology access and use (cell phone, email). Ninety-five percent indicated that they would use the mobile application allowing EHR access. The majority (79%) of participants were either satisfied or very satisfied with the MyChart Genius program and none expressed dissatisfaction. Survey results reveal that patients are interested in communicating via technology with their health care providers using e-mail and text messages regarding appointment reminders, laboratory results, and general health messages. Observed barriers to the sign-up process included: consistent Genius presence in the clinic, patient illiteracy, disinterest, and acute illness.

**Conclusions:** Use of the MyChart Genius program demonstrates that the availability of youth-friendly tech support during clinical visits is a feasible, acceptable, and effective for increasing portal activation by youth. Preferences for future communication with health care providers suggests a need for enhanced technology integration to better individualize communication types for optimal care delivery.

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**BANKING THE FUTURE: ADOLESCENT CAPACITY TO CONSENT TO BIOBANK RESEARCH**

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**Purpose:** Biobanking includes the long-term storage of biologic samples linked to personal health information. Pediatric biobanks are crucial to understanding the long-term consequences of disease. Given the long-term implications for confidentiality, adolescents should participate in the biobank consent process. Adapting a validated adult capacity assessment tool, we examined predictors of adolescent capacity to consent to biobanking research.

**Methods:** Adolescents and young adults ages 12-24 were recruited from primary care clinics, schools, and the community. Participants were underwent a standard consent process for the Indiana Biobank (an existing and actively recruiting biobank), followed by an adaptation of the validated adult tool, the Macarthur Competency Assessment Tool for Clinical Research (MacCAT-CR). The MacCAT-CR has 18 items divided into 4 subscales: understanding of the study information (10 items, range 0-20), appreciation for the significance of the decision to participate or not (3 items, range 0-6), rational manipulation of information & reasoning (4 items, range 0-8), and the ability to express a choice (1 item,
range 0-2. Other measures included health literacy, as measured by the Rapid Estimate of Adult Learning in Medicine (REALM, 66 items, range 0-66), socioeconomic status, as measured by the Family Affluence Scale (4 items, range 0-9), and the presence of a chronic illness (3 items on presence of a chronic illness, medication and treatments, and hospitalization). Data were analyzed using SPSS for bivariate analyses and linear regression.

Results: We enrolled 78 adolescents, mean age 17.0 +/- 2.8 years), 63% female. The mean REALM score was 60.8, or approximately 8th-9th grade reading level. Mean FAS score was 6.5 (SD=1.8) corresponding to upper middle class. Overall decision-making capacity was high. The MacCAT-CR overall score was 30.5 (SD=4.7) out of a total of 36 points, with subscales showing similar results. Participants had a mean score of 16.44 (SD=2.98) on the understanding section, 5.27 (SD=1.05) on the appreciation section, 6.83 (SD=1.47) on the reasoning section, and 100% of the sample responding to the question “do you have a choice to participate in the study” correctly. On regression analysis, age and chronic illness were not significant predictors, and were removed from the model. The final model consisted of REALM and FAS scores as predictive variables and had an R2 of 56.4%. Beta values for predictors were .68 for the REALM and .26 for FAS.

Conclusions: Adolescent capacity to consent was similar to adults, and most strongly associated with family affluence and medical literacy. This contrasts starkly with the age-based criterion for providing consent, and provides insights into ways to ethically involve youth in biobanking and similar research.

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DEVELOPMENT OF THE LOCATION INITIATED INDIVIDUALIZED TEXTS FOR AFRICAN AMERICAN ADOLESCENT HEALTH (LIITA3H) MOBILE APPLICATION
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Purpose: African American (AA) adolescents have a disproportionately high prevalence of obesity compared to their Caucasian peers. This may be due in part to a greater likelihood of living in environments with a high density of fast food and a greater likelihood of consuming calorie dense, low nutrient foods. The purpose of this study was to develop a tailored mobile application that could help AA adolescents make healthier food choices at the point of sale.

Methods: We prototyped a system that identified when students arrived in food venues and delivered tailored messages specific to each venue. Messages were crafted from the students food preferences, cultural perceptions and venues garnered via focus groups and interviews conducted with AA adolescents (n=8). Students also responded about their eating experience by annotating a photo of their selections. The application: 1) Enabled each student to mark a set of venues during a ‘training period’. When students arrived at an eating location it was added to their location list. The latitude, longitude, and an initial radius were set for that location, but updated as data were collected; 2)
Monitored location with a “fused provider” service. When the participant was outside the radius of an eating venue, we categorized their proximity to nearest venues as cold, warm, or hot; which set the next poll interval. This conserved battery, and allowed fine location polling near venues; 3) Recognized and confirmed an “intent to eat” at an eating location prior to delivering notifications (when a participant is detected to be at a venue within windows for breakfast, lunch, or dinner). Only one trigger was allowed within each window. We pilot tested the intervention over 30 days with 5 AA adolescents from a High School in Detroit.

**Results:** Technology - Participants registered an average of 2.2 (range 1 to 4) locations. They returned to at least one registered venue and received 3 to 62 messages. The number of at-venue polls per detected venue ranged from 0 to 2760, reflecting a wide range of durations spent at venues. Only the initial arrival generated a food message. Proximity verification by polling (hot, warm, cold) found a wide variation in typical proximity venues. Tailoring - Participants found the technology easy to use but wished to have it more customizable to their individual preferences. Efforts to culturally and individually tailor the messages to their preferences were generally successful as they indicated that the messages seemed relevant to them.

**Conclusions:** The mobile application successfully identified when adolescents entered an eating venue with an intention to eat and delivered actionable and appropriate food recommendations for the eating venues they selected. This new technology identified their location the majority of the time and the messages delivered were deemed helpful. This offers the potential to provide tailored content to adolescents based on their location. Further work will is required to refine the technology and to determine whether the application positively impacts food choices and ultimately weight status.

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