

184.

THE CREATION OF STAKEHOLDER-BASED CLINICAL AND MOBILE BASED PROGRAMS TO ASSIST IN TRANSITION AND TRANSFER TO ADULT CARE FOR A DIVERSE GROUP OF CONGENITAL HEART DISEASE ADOLESCENTS

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Purpose: Congenital heart diseases (CHDs) are the most common type of birth defects. Improvements in CHD care have led to roughly 1.4 million survivors reaching adulthood. Unfortunately, <30% of adults with CHD are seen by adult CHD physicians, and few formal CHD transition-to-adult programs exist. The objective of this project was to first complete a stakeholder needs assessment to inform the knowledge gaps, transition readiness, and delivery of transition education for a diverse group of adolescents with CHD. Second, to develop the workflow, educational content, and electronic medical record (EMR) components for a clinical and mobile-based education with the assistance of an adolescent CHD expert panel.

Methods: We conducted a literature search for best practices and CHD guidelines in transition medicine. We then conducted individual interviews with pediatric cardiologists, adult CHD specialists, parents and their CHD adolescents to understand acceptable delivery of education both in clinic and via a mobile application. We assessed knowledge via CHD questionnaires we created, and transition readiness via the Transition Q. We then partnered with clinic staff, 2 adolescent CHD expert panels, transition experts, and electronic medical record teams to further determine educational content, delivery as well as clinical and mobile application design.

Results: We completed 327 individual interviews with CHD adolescents ages 15–22 years. 78.2% had moderate or severe CHD complexity. 41.6% of CHD adolescents were female, 12.7% were African American, and 35.8% were Latino. 36.5% of patients had public insurance. 42.2% of patients aged 15–17 years and 47.9% aged 18–22 years had minimal understanding of their CHD, but an interest in learning. Transition readiness scores reflected an average of 49.4% readiness for those aged 15–17 and 58.6% for those aged 18–22. Clinical educational requests were accomplished including same-day delivery at the cardiology appointment, and transition education to be delivered by a transition nurse and social worker. EMR requests included tracking of education and a deliverable medical summary, which we built. For the mobile application, adolescents expressed the need for a tailored application to their specific CHD, question-answer exchange, a blog-type CHD forum, and a transition checklist. We concomitantly built a mobile application incorporating educational content, assessments of transition readiness and knowledge, a CHD diagram, a medical summary, a blog, checklist, and question/answer space.

Conclusions: Based on our data of average CHD knowledge and transition readiness scores, CHD adolescents are largely not prepared for transition and transfer to adult care. The vast majority of adolescents found education in clinic and via a mobile application acceptable. We were able to create a mobile application and a clinical education program with our stakeholders including CHD adolescents to aid in the CHD transition process. Next steps are to begin use of EMR educational and medical summary templates, and to further build CHD

educational content, to conduct mobile application usability testing, and to use focus groups to refine our current mobile application.

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RESEARCH POSTER SESSION II: CHRONIC ILLNESS

185.

YOUTHS WITH CHRONIC CONDITIONS SHOW NO DIRECT ASSOCIATION WITH RISK BEHAVIORS

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Purpose: Using a non-categorical approach, the aim of our study was to compare risk behaviors between youths living with a chronic condition and their healthy peers, controlling for the severity of the condition represented by limitations in daily life activities.

Methods: Data were obtained from the baseline wave of the GenerationFree study during the 2014–2015 school-year. Students aged 15 to 24 years in post-mandatory education were invited to participate in a web-based self-administered anonymous questionnaire which aimed to assess their lifestyles. The sample (N = 5179) was divided into youths with chronic conditions without limitations (N = 536; 10.4%), youths with limitations (N = 114; 2.2%), and a control group (CG; N = 4529; 87.4 %). Groups were compared on internalizing (perceived health status, vision of their future, emotional wellbeing) and externalizing behaviors (substance use [tobacco, alcohol, cannabis, other drugs], gambling, excessive internet use, disordered eating, violent and antisocial acts) controlling for potential confounders (gender, age, pubertal timing, academic track, socioeconomic status and family structure). Statistical analyses were carried through a structural equation modeling (SEM). Results are given as unstandardized coefficients.

Results: Overall, youths with chronic conditions showed an association with internalizing behaviors (coefficient: .80) but not with externalizing ones. In fact, the connection with externalizing behaviors was indirect via the internalizing factors (.32). Perceived health status' coefficient being fixed as 1, the coefficient between youths with chronic conditions and latent internalizing variables showed that they were significantly more likely to report poor emotional wellbeing (coefficient: -1.64) and a negative vision of their future (-2.03). It was observed that youths with chronic conditions reporting psychological issues were more likely to adopt every externalizing behavior. Through an indirect path, and using current smoking as the reference fixed variable, youths with chronic conditions showed positive associations with all externalizing behaviors, ranging from .09 for disordered eating to 1.55 for the use of illegal drugs other than cannabis. Analyzing separately youths with chronic conditions that limit daily life activities and those without limitations, the results did not change substantially. However, the association with internalizing behaviors was much higher for those reporting limitations than for those not reporting them (2.21 vs. .44, respectively).

Conclusions: Our results show that there is no direct link between suffering from a chronic condition and adopting risk behaviors, but rather that the association is indirect through internalizing factors, mainly a negative view of their future. From a prevention perspective, health professionals should address emotional wellbeing and

perception of the future rather than focus exclusively on the effects of risk behaviors on specific diseases. Literature indicates that envisioning a positive future is critical to fostering resilience in at-risk youths and thus reducing risk behaviors. The results highlight the need for these youths, especially those with limiting conditions, to have a life plan including educational and vocational goals instead of reducing it to a plan centered on their condition.

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186.

BIOFEEDBACK FOR MUSCULOSKELETAL PAIN—DOES IT WORK AND WHAT FACTORS ARE ASSOCIATED WITH SUCCESSFUL OUTCOMES?

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Purpose: Biofeedback is effective for multiple pain conditions in adults, and for headaches in children. There is little evidence regarding efficacy of biofeedback for pediatric musculoskeletal pain. This retrospective chart review investigates: 1) outcomes of biofeedback for pediatric musculoskeletal pain, and 2) factors associated with successful treatment. These data will inform pediatric clinical guidelines for efficacy and appropriate use of biofeedback.

Methods: We reviewed charts of patients who underwent biofeedback at a large urban center between January 2008 to April 2016. Selection criteria included: 1) diagnosis of chronic musculoskeletal pain, and 2) completed ≥ 6 sessions of biofeedback. We initially generated descriptive statistics of the population and calculated the proportion achieving treatment "success" as defined in prior studies (decrease in pain score of ≥ 3 points or $\geq 50\%$ on a self-reported 1–10 scale). We also calculated the following secondary outcomes: 1) proportion achieving any decrease in average pain score in the past week compared with pre-treatment, 2) proportion with decrease in the number of pain days per week compared with pre-treatment, and 3) proportion that were completely pain free by end of biofeedback treatment. We then performed linear or logistic regressions as appropriate to determine demographic (gender, age, race/ethnicity), historical (prior medication/non-medication treatments), and psychosocial (depression and anxiety symptoms, sleep latency/duration) factors that were associated with treatment success/non-success and secondary outcomes.

Results: There were 40 eligible biofeedback patients. Patients were majority female (85%), 70% white, and were an average age of 15.17 years (range: 10–19 years). Average duration of pain prior to biofeedback was 2.3 years. Most patients had back pain (82.5%) or neck pain (15%). Forty-five percent met criteria for treatment success, 70% achieved some decrease in pain score, 46% experienced a decrease in the number of pain days, and 25% of patients were pain free by the end of treatment. Having a history of prior treatment with physical therapy, massage, chiropractic, and/or acupuncture was negatively associated with several outcomes including lower likelihood of successful treatment based on the above definition ($p = .02$), smaller average decrease in pain score ($p = .02$), and smaller decreases in number of pain days per week ($p = .01$). Prior use of medications, in contrast, was not associated with differences in success rates or sec-

ondary outcomes. Having a higher pain score before treatment was associated with improved odds of treatment success ($p < .001$). Female patients had a smaller average decrease in pain days per week by end of treatment compared with males ($p = .03$). Larger decreases depression (Children's Depression Inventory) scores and in self-reported sleep latency by the end of the treatment period were associated with greater decrease in pain days per week ($p = .03$ and $.02$, respectively).

Conclusions: Biofeedback appears to be effective for some patients with musculoskeletal pain, particularly for those who have not undergone prior physical therapy, massage, chiropractic or acupuncture, and those who have high pain scores prior to treatment. Gender may also influence some aspects of response. More research is needed to confirm/extend findings to better understand which pediatric patients with musculoskeletal pain will respond to biofeedback.

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187.

THE GREATER MANCHESTER CHILDREN AND YOUNG PERSON'S INHALER TECHNIQUE SCHOOL SERVICE DEVELOPMENT PROJECT

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Purpose: Community/retail pharmacists in Greater Manchester (GM) have been providing an inhaler check service to adults for several years. Many adults using this pharmacy service report that they have had their inhaler since childhood/adolescence and have never been shown how to use it. There have also been asthma-related deaths in GM schools in recent years. This led to a bid for funding to bring the pharmacist-led service into schools, for children and young people (CYP) to master their inhaler at an early age—and hopefully to sustain good technique into adulthood with associated positive health outcomes.

Methods: The program team invited a diverse sample of schools to participate across Greater Manchester. The initial program format was to give a presentation to a group of CYP with inhalers and their parent/caregivers about asthma, and then for two pharmacists to do family consultations whilst those waiting did asthma-related teaching activities. In a later revision, the whole school received a presentation about asthma and then the CYP/families using inhalers could book individual consultations with a pharmacist in school afterwards. Each family was offered an initial check and a follow-up check 6–8 weeks later. CYP in secondary schools could attend alone, with prior parental consent. This development project was funded by NHS England (Greater Manchester and Lancashire).

Results: Eighty-eight CYP aged 4–16 from fifteen schools took part. There was good diversity among participants in terms of age, gender, ethnicity and locality deprivation. These results derive from short anonymous evaluation surveys administered to CYP and parents/caregivers at the end of each session ($n = 90$ in Session 1 and $n = 41$ in Session 2), 65 students attending the revised whole-school presentation and 8 staff. Most CYP/families felt more knowledgeable (96.7%) and confident (95.6%) about inhalers after Session 1, and more confident (85.6%) about spotting emergency signs of asthma. Some (22.0%) spoke to a community pharmacist about inhalers between the two sessions, and over half (56.1%) felt more likely to ask a pharmacist for advice about inhalers since the program. Reports of urgent asthma-related action taken before Session 1 and Session 2 (such as