



Div 54 Society of Pediatric Psychology Adherence Special Interest Group

Spring 2020 Newsletter

Our annual newsletter highlights the innovative work of our members and provides updates on Adherence SIG activities. Consistent with the goals of the Adherence SIG, our hope is that this newsletter will disseminate research, facilitate clinical collaborations, and support the training and mentorship of our students and fellows.

We appreciate your continued involvement in the Adherence SIG!

Leadership Updates

Our leadership team will transition following SPPAC 2020.

We would like to extend our warmest welcome to our incoming Adherence SIG leadership!

SIG Chair: Julia Carmody, PhD

SIG Co-Chair: Jill Plevinsky, PhD

Assessment Committee Leader: Vacant

Dissemination Committee Leader: Lindsay Durkin, MS

Intervention Committee Leader: Kim Klages, MS

Communication Chair: Kate Gamwell, PhD

We offer our deepest thanks to our outgoing Adherence SIG leaders.

SIG Chair: Ana Gutierrez-Colina, PhD

SIG Co-Chair: Julia Carmody, PhD

Assessment Committee Leader: Alexa Stern, MA

Dissemination Committee Leader: Jeanette Iskander, MA

Intervention Committee Leader: Kim Klages, MS & Jill Plevinsky, PhD

To join the Adherence SIG email Julia Carmody (julia.carmody@childrens.harvard.edu)

Website Content and Updates

Please visit our website: <https://div54adherencesig.weebly.com>

- ***NEW table listing over 60 different validated adherence questionnaires***, sorted by disease group with links to each publication.
- PDFs of publicly available adherence assessment measures, such as the Self-Care Inventory, Diabetes Self-Management Questionnaire, Medical Adherence Measure, AMBS and PMBS.
- Clinical resources including a ***NEW peer-reviewed clinical handout on promoting adherence during transition to adult care*** for adolescents/young adults and their caregivers
- Adherence Intervention Library –find up-to-date research on adherence interventions by condition type. This page includes links to published manuscripts and abstract summaries for each study created by Adherence SIG volunteers.
- List of medication adherence phone apps.
- Meta-Analyses and reviews of adherence interventions.

Have other ideas for website content? Fantastic! Contact one of the Adherence SIG leaders!



Presentations by our members at SPPAC 2020!

Virtual symposia Thursday March 19 1:15 – 2:30 CT

Examining associations between substance use, self-management, and health outcomes in adolescents and young adults (AYAs) with IBD. Authors: Jill M. Plevinsky, Ph.D., Sarah J. Beal, Ph.D., Michele H. Maddux, Ph.D., Rachel N. Greenley, Ph.D., Kevin A. Hommel, Ph.D.

Using Ecological Momentary Assessment Data to Inform the Development of a Just-in-Time Adaptive Adherence Intervention for AYA With Leukemia. Alexandra M. Psihogios, PhD, Lisa A. Schwartz, PhD, Yimei Li, PhD, Leslie Kerson, MD, MSCE, MSED and Lamia P. Barakat, PhD

SPPAC Posters (presentations via Twitter)

Alexa Stern, M.A., Adrien M. Winning, B.S., Angelica Ortiz, & Grayson N. Holmbeck, Ph.D.
Neuropsychological functioning and parenting behaviors as predictors of growth trajectories in in medical responsibility among youth with spina bifida.

Wetter, S.E., Schmidt, M., Rietta, C., Gutierrez-Colina, A., Neely, T., Glaser, N., Wagner, J.L., Smith, G., Huzsti, H., Guilfoyle, S.M., Patel, A.D., & Modi, A.C. **Use of empathy mapping to develop a pediatric epilepsy mHealth adherence intervention.**

Ewell, T., Durkin, K., Hynes, L., Lilly, C., Skoner, D., & Duncan, C. **Evaluating the impact of child and caregiver self-efficacy on daily inhaler use in pediatric asthma patients.**

Student Poster Award

Congratulations Kelly Rea, BA
on her award-winning work!



Poster session 1 (Thursday 3-4PM). Healthcare Settings Among Pediatric Solid Organ Transplant Recipients: Associations with Transfer Success

Given increased survivorship rates, adolescent and young adult (AYA) transplant recipients are increasingly transitioning to adult healthcare settings. However, transition is associated with poor medication adherence. Data on post-transfer adherence to multiple aspects of the medical regimen (e.g., medication adherence, clinic attendance) among AYA transplant recipients remains limited. As such, this study examined adherence to immunosuppression medication during transition and relations to transfer success.

Participants included 49 AYAs with heart, kidney, or liver transplants recently transferred to adult healthcare (Mage at transfer=20.62 years; SD=0.52). Adult clinic visit within one year of the last pediatric visit indicated transfer success, with the majority of the current sample (77%) successfully transferring. Medication Level Variability Index (MLVI), an objective measure of tacrolimus adherence, was collected in the year pre-transfer and two years post-transfer. Successfully transferred AYAs were further from transplant, $t(26.91)=3.00$, $p<.01$, older at transfer, $t(47)=1.99$, $p=.052$, and with less post-transfer variability in medication-taking, $t(30)=2.51$, $p=.02$. Successful transfers were significantly more likely to be classified adherent post-transfer based on MLVI, $X^2(1, N=32)=6.68$, $p=.02$. AYAs who were non-adherent pre-transfer were significantly more likely to be non-adherent post-transfer, $X^2(1, N=32)=9.79$, $p<.01$.

The current study suggests that, without intervention, pre-transfer medication non-adherence persists into adult healthcare settings, underscoring the importance of continuing attention to medication adherence in adult healthcare. Future research should test the feasibility of identifying patients at-risk for nonadherence via those known to demonstrate nonadherence or adherence barriers pre-transfer, as well as characteristics of patients not modifiable through intervention (i.e., patient age, time since transplant). Additionally, future studies should assess the impact of pediatric non-adherence interventions after transfer and examine post-transfer medical and psychosocial factors related to transfer success and adherence.

MEMBER GRANTS

Congratulations to all of the Adherence SIG members receiving grant funding for adherence-related research during the past year!

Alexandra M. Psihogios, PI

Using Real Time Mobile Health Approaches to Understand and Promote Oral Chemotherapy Adherence in Adolescents and Young Adults with Leukemia. National Cancer Institute, K08CA241335-01, Project Period: 9/2019-9/2024

Rachelle Ramsey, PI

Randomized Control Trial of Technology-Assisted Stepped Care Intervention to Improve Adherence in Adolescents with Asthma. NHLBI K23

Avani Modi, Co-investigator

Improving adherence in adolescents and young adults with bipolar disorder. NIH, NIMH (R34 MH117206-01), Entire Project Period: 6/1/2019-5/31/2022, (MPI: Sajatavi & Delbello)

Avani Modi & Kimberly Driscoll, PIs

Diabetes Journey: From systematic screening to intervention, National Institute for Diabetes, Digestive, and Kidney (R01 DK121295-01), Entire Project Period: 4/2019-3/2023

Christina Duncan, Co-Investigator

Developing an adapted parent-youth teamwork intervention to improve medication adherence among adolescents with asthma: A feasibility study. Medical Research Council, United Kingdom, Period: 04/01/2019 – 09/01/2020 (PI: P Rackow)

MEMBER PUBLICATIONS

ASTHMA

Hynes, L., Durkin, K., Williford, D.N., Smith, H., Skoner, D., Lilly, C., Kothari, V., McSharry, J., & Duncan, C.L. (2019). Comparing written versus pictorial asthma action plans to improve asthma management and health outcomes among children and adolescents: Protocol of a pilot and feasibility randomized controlled trial. *Journal of Medical Internet Research: Research Protocol*, 8(6), e11733. DOI: 10.2196/11733

Hoch, H., Ramsey, R.R., & Federico, MD. (in press). They just don't take their medicines: Reframing medication adherence in asthma from frustration to opportunity. *Pediatric Pulmonology*.

Kenyon, C.C., Sundar, K.G., Gruschow, S.M., Quarshie, W.O., Feudtner, C., Bryant-Stephens, T.C., & Miller, V.A. (2019). Tailored medication adherence incentives for high risk children with asthma: A pilot study. *Journal of Asthma*. doi.org/10.1080/02770903.2019.1648503

Kenyon, C.C., Gruschow, S.M., Quarshie, W.O., Griffis, H., Leach, M.C., Zorc, J.J., Bryant-Stephens, T.C., Miller, V.A., Feudtner, C. (2019). Controller adherence following hospital discharge in high risk children: A pilot randomized trial of text message reminders. *Journal of Asthma*, 56(1), 95-103.

Ramsey, R.R., Carmody, J., Voorhees, S., Warning, A., Cushing, C.C., Guilbert, T.W., Hommel, K.A., & Fedele, D.A. (2019). A Systematic Evaluation of Asthma Management Apps Examining Behavior Change Techniques. *Journal of Allergy and Clinical Immunology: In Practice*, 7(8) 2583-2591. 30.

Ramsey, R.R., Plevinsky, J.M., Kollin, S.R., Gibler, R.C., Guilbert, T.W., & Hommel, K. A. (Epub ahead of print). Systematic review of digital interventions for pediatric asthma management. *Journal of Allergy and Clinical Immunology: In Practice*. pii: S2213-2198(19)31037-2. doi: 10.1016/j.jaip.2019.12.013. 33.

Lin, N. Y., Ramsey, R.R., Miller, J. L., McDowell, K.M., Zhang, N., Hommel, K. A., & Guilbert, T. W. (in press). Telehealth delivery of adherence and medication management system improves outcomes in children with asthma. *Pediatric Pulmonology*.

CANCER

Psihogios, A.M., Schwartz, L.A., Deatrck, J.A., Ver Hoeve, E.S., Anderson, L.M., Wartman, E.C., & Szalda, D (2019). Preferences for cancer survivorship care among adolescents and young adults who experienced healthcare transitions and their parents. *Journal of Cancer Survivorship* 13(4), 620-631.

McGrady, M. E., & Pai, A. L. H. (2019). A systematic review of rates, outcomes, and predictors of medication non-adherence among adolescents and young adults with cancer. *Journal of Adolescent and Young Adult Oncology*, 8, 485-494. doi: 10.1089/jayao.2018.0160. PMID: 31038372

Schwartz, L.A., Psihogios, A.M., Henry-Moss, D., Daniel, L., Ver Hoeve, E.S., Velazquez-Martin, B., Butler, E., Hobbie, W.L., Buchanan Lunsford, N., Sabatino, S.A., Barakat, L.P., Ginsberg, J.P., Fleisher, L., Deatrck, J.A., Jacobs, L.A., O'Hagan, B., Anderson, L., Fredericks, E., Amaral, S., Dowshen, N., Houston, K., Vachani, C., Hampshire, M.K., Metz, J.M., Hill-Kayser, C.E., & Szalda, D. (2019). Iterative development of a mHealth intervention for adolescent and young adult survivors of childhood cancer. *Clinical Practice in Pediatric Psychology*, 7(1), 31-43.

Schwartz, L.A., Daniel, L.C., Henry-Moss, D., Bonafide, C.P., Li, Y., Psihogios, A.M., Butler, E.S., Szalda, D., Ver Hoeve, E.S., Hobbie, W.L., Dowshen, N.L., Pierce, L., Kersun, L.S., & Barakat, L.P. (2020). Feasibility and acceptability of a pilot tailored text messaging intervention for adolescents and young adults completing cancer treatment. *Psycho-oncology*, 29(1),164-172.

CYSTIC FIBROSIS

Murphy, C. & Miller, V.A. (2019). Concurrent and longitudinal associations among parenting style, responsibility, and adherence in youth with cystic fibrosis. *Children's Health Care*. doi.org/10.1080/02739615.2019.1616295

IBD

Carmody, J.K., Plevinsky, J.M., Peugh, J., Lobato, D., LeLeiko, N.S., Hyams, J.S., Denson, L.A., & Hommel, K.A. (2019). Longitudinal adherence to mesalamine predicts treatment escalation in pediatric ulcerative colitis. *Alimentary Pharmacology & Therapeutics*, 50, 911-918. doi: 10.1111/apt.15445 1.

DIABETES

Gutierrez-Colina, A.M., Corathers, S., Beal, S., Baugh, H., Nause, K., & Kichler, J. (in press). Young Adults with Type 1 Diabetes Preparing to Transition to Adult Care: Psychosocial Functioning and Associations with self-Management and Health Outcomes. *Diabetes Spectrum*.

Silva, K. & Miller, V.A. (In press). Does self-efficacy mediate the link between impulse control and diabetes adherence from late childhood to late adolescence? A longitudinal mediation analysis. *Journal of Pediatric Psychology*.

Miller, V.A. & Jawad, A.J. (2019). Decision making involvement and prediction of adherence in youth with type 1 diabetes: A cohort sequential study. *Journal of Pediatric Psychology*, 44(1), 61-71.

Silva, K. & Miller, V.A. (2019). The role of cognitive and psychosocial maturity in type 1 diabetes management. *Journal of Adolescent Health*, 64(5), 622-630.

SICKLE CELL

Creary, S., Modi, A.C., Stanek, J., Chisolm, D., O'Brien, S., Nwankwo, C., and Crosby, L.E. (2019). Allocation of Treatment Responsibility and Adherence to Hydroxyurea Among Adolescents with Sickle Cell Disease, *Journal of Pediatric Psychology*, 44 (10), 1196-1204. doi: 10.1093/jpepsy/jsz061. PMID: PMC6823103

OTHER

Psihogios, A.M., Gutierrez-Colina, A.M., Iskander, J.M., Wasserman, R.M., & Ramsey, R.R. (2020). Adherence knowledge and education needs among pediatric psychology trainees: A needs assessment and recommendations. *Clinical Practice in Pediatric Psychology*, 8(1), 45–55.

Plevinsky, J.M., Gutierrez-Colina, A.M., Carmody, J.K., Hommel, K.A., Crosby, L.E., McGrady, M.E., Pai, A.L.H., Ramsey, R.R., & Modi, A.C. (Epub ahead of print). Patient-reported outcomes for pediatric adherence and self-management: A systematic review. *Journal of Pediatric Psychology*. pii: jsz096. doi: 10.1093/jpepsy/jsz096.

Pascoe, J.E., Sawnani, H., Hater, B., Sketch, M., & Modi, A.C. (2019). Understanding Adherence to Noninvasive Ventilation in Youth with Duchenne Muscular Dystrophy. *Pediatric Pulmonology*, 54(12), 2035-2043. doi: 10.1002/ppul.24484.

Harry, O., Crosby, L.E., Smith, A.W., Favier, L., Aljaberi, N., Ting, T., Huggins, J., & Modi, A.C. (2019). Self-Management and Adherence in Childhood-Onset Systemic Lupus Erythematosus: What Are We Missing? *Lupus*, 28(5), 642-650. PMID: PMC6506349.

MEMBER PRESENTATIONS AT OTHER CONFERENCES

Duncan, C. L., Lindwall, J., Muther, E., Nelson, E., Ahrabi-Nejad, C., White, M., Moffett, K., Saavedra, M., Prickett, M., & Polineni, D. (2019, October). Focus group & qualitative interviews inform development of a tele-coaching adherence promotion intervention for adolescents and young adults with cystic fibrosis. Poster presentation at the annual North American Cystic Fibrosis Conference, Nashville, TN.

Muther, E., Lindwall, J., Bord, E., Polineni, D., & Duncan, C. (2019, October). A tele-coaching intervention to improve adherence in adolescents and young adults with cystic fibrosis. Poster presentation at the annual North American Cystic Fibrosis Conference, Nashville, TN.

Polineni, D., Durkin, K., Psoter, K., Eckmann, T., Greenburg, J., Goodman, A., & Duncan, C. (2019, October). Feasibility of self-reported digital photography to monitor adherence to high frequency chest wall oscillation therapy. Poster presentation at the annual North American Cystic Fibrosis Conference, Nashville, TN.

Duncan, C., Durkin, K., Ruvalcaba, E., Bord, E., & Polineni, D. (2019, September). Development and validation of a new measure of adherence in cystic fibrosis care. Poster presentation at the 33rd annual meeting of the European Health Psychology Society.

Dubrovnik, HRV. Durkin, K., Harrah, G., Hynes, L., Ewell, T., Williford, D., Skoner, D., Lilly, C., & Duncan, C. (2019, September). Asthma action plan intervention effects over time on miscarried helping, and parent and youth self-efficacy in asthma management. Oral presentation at the 33rd annual meeting of the European Health Psychology Society, Dubrovnik, HRV.

MEMBER CLINICAL INITIATIVES

At the University of Michigan, Dana Albright, PhD and colleagues have standardized assessment of six key habits related to Type 1 Diabetes and are preparing a manuscript on the links to health outcomes. Additionally, Dr. Albright and colleagues have created two clinical tools to assess barriers to adherence to be used by medical and psychosocial providers alike to identify barriers and problem-solve strategies to improve adherence.

Congratulations to our members on a very productive year! We look forward to continuing to highlight research and clinical initiatives!