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SYMPOSIUM 17

INNOVATING FOR IMPACT: PARTICIPANT, CLINICAL, EDUCATIONAL, AND RESEARCH LESSONS LEARNED FROM THE COURSE AND OUTCOME OF BIPOLAR YOUTH (COBY) STUDY



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Objectives: This Symposium will provide an overview of lessons learned from the Course and Outcome of Bipolar Youth (COBY) and Predicting Adult Outcomes of Bipolar Youth (PROBY) studies, which have followed the same cohort longitudinally for up to 23 years. Data will be presented on impacts from lived experience, clinical, educational, and research perspectives.

Methods: At intake, COBY enrolled 413 youth, ages 7-17 years. Participants were interviewed with standard instruments on average every 7.4 months, for a median duration of 91.9 months (7.7 years, range: 6 months to 228 months), with a retention rate of 78%. Heather Hower, DSW, will provide an overview of diagnostic controversies that shaped the aims of the COBY study. Danella Hafeman, MD, PhD, will share bipolar spectrum disorder lived experience perspectives. Ben Goldstein, MD, PhD, will present data on clinical advances for youth, young adults, and families. Jeff Hunt, MD, will discuss the impact of changing conceptualizations of early-onset bipolar disorders on educational training curricula. Boris Birmaher, MD, will describe the 23-year evolution of COBY/PROBY study findings on the course, outcomes, and risk factors of these disorders.

Results: The COBY study was designed in 2000 in part to resolve the diagnostic controversy about the validity of pediatric bipolar disorders. Once thought to be nonexistent in youth, and then a chronic disorder with adult onset, the 23 years of COBY/PROBY findings have indicated that early-onset bipolar disorders have many potential courses and outcomes, including predominantly euthymic, as highlighted in lived-experience perspectives. Clinical advances have contributed to improved prognoses, while changing conceptualizations have better informed training approaches. Research findings from this cohort suggest additional pathways for meaningful inclusion of lived experience, risk prediction, and precision medicine.

Conclusions: Follow-up data from COBY and PROBY have been a valuable resource for better understanding the course and outcome of bipolar disorders in youth and young adults. These findings provide an overview of lessons learned with implications for personal, clinical, educational, and research areas of innovation.

BRD, LONG, RF

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17.1 LIVED-EXPERIENCE PERSPECTIVES FROM THE COURSE AND OUTCOME OF BIPOLAR YOUTH (COBY) STUDY: DIAGNOSES, SYMPTOMS, FUNCTIONING, AND TREATMENT



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Objectives: In considering the diagnosis, course, and outcomes of youth with early-onset bipolar spectrum disorder (BD), it is critical to design careful longitudinal follow-up through young adulthood with validated measures. However, if we focus solely on quantitative outcomes, it is possible to lose track of the true qualitative impact that BD, correct diagnosis, and treatment have on the young people we serve. Thus, hearing lived experience stories is crucial to motivate our studies, as well as to inform the questions we ask and the interpretations we derive from our data. This presentation will highlight stories of young people with BD, providing narrative perspectives complementing the longitudinal analyses of the Course and Outcome of Bipolar Youth (COBY) study.

Methods: We will present stories of young people with BD, in their own words, from the University of Pittsburgh Medical Center COBY study site. These

narratives will be obtained from 3 sources: 1) previous COBY participants, some of whom are still in treatment in the Child and Adolescent Bipolar Services (CABS) clinic; 2) current CABS young adult Youth Advisory Board participants, who have focused their efforts on education and combatting stigma; and 3) CABS patients, who will be invited to anonymously share their stories of living with BD. These narratives will be collected via writing or audio/video recording, depending on individual comfort levels; all contributors will have the opportunity to approve the use of their narratives in the final presentation.

Results: The narratives will focus on themes found in the other symposium presentations: 1) the (often long) journey to a correct diagnosis and the impact on their lives; 2) experience with treatment, including what has been most beneficial and most challenging; and 3) impact on functioning, with strategies the youth have found most effective to maintain wellness.

Conclusions: The goal of this presentation is to bring us beyond the numbers, to the reason that we do this work: to improve the lives of young people with BD. We hope that these important perspectives highlight the significance of studying BD in youth, the impact that a correct diagnosis and evidence-based treatment can have on young people, and the continued challenges faced by adolescents and young adults that future research should address.

BRD, LONG, RF

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17.2 BEYOND MOOD: DEMOGRAPHIC, CLINICAL, FAMILIAL, AND ENVIRONMENTAL CONSIDERATIONS IN THE ASSESSMENT AND MANAGEMENT OF EARLY-ONSET BIPOLAR DISORDER



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Objectives: While bipolar disorder (BD) is defined by episodes of hypo/mania and depression, there are multiple other factors that contribute to symptomatic burden, functional impairment, and risk in this population. Over 2 decades, the Course and Outcome of Bipolar Youth (COBY) study generated key findings that are relevant to the assessment and treatment of youth and young adults with BD.

Methods: A series of longitudinal studies evaluated demographic (eg, age and sex differences), clinical (eg, comorbidity, suicidality, treatment), familial (eg, family psychiatric history), and environmental (eg, socioeconomic status, life adversity) factors, and their associations with symptoms, functioning, and risk.

Results: There are relatively few sex differences in the course of youth BD. Frequency of mental health treatment visits declines from childhood to young adulthood, independent of socioeconomic status, symptom burden, and functioning. Anxiety disorders are common, accumulate, and persist. One-fifth of participants experienced suicide attempts within 5 years; predictors included depression severity, family history of depression, and substance use disorders (SUD). One-third of participants developed SUD; proximal predictors included greater hypo/manic symptom severity and less lithium exposure. While based on observational, naturalistic data, lithium is associated with reductions in suicide attempts, depression severity, aggression, and impairment across age groups. One-third of participants reported a history of physical/sexual abuse at intake and/or follow-up. Risk factors varied by type of abuse, but positive friendships were protective for both types. One-fifth of participants had metabolic syndrome, more than double vs the general population.

Conclusions: Collectively, these findings align strongly with those observed among adults with BD. Quality of family relationships and friendships were relevant to multiple important outcomes. There was accrual of psychiatric and physical comorbidity and suicide attempts, which varied according to treatment characteristics. The contrast between overall illness severity and complexity increasing with time, in parallel with decreasing treatment visits, highlights the importance of sustained access to regular follow-up.

BRD, LONG, RF

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