Tuberous Sclerosis Complex (TSC) is a dominantly inherited genetic disorder that causes hamartomatous lesions throughout the body, resulting in a wide spectrum of disease. Many of the serious complications of TSC, such as epilepsy, autism, intellectual disability and psychiatric disorders, reflect the brain involvement that occurs in most cases. Developmental delay in TSC has been quite extensively studied; however, not as much is known about the increased prevalence of psychiatric disorders (anxiety disorders in 9-56% and depression in 19-43% of populations studied) seen in individuals with TSC and normal intelligence. Therefore, it is important to study the beliefs of affected individuals regarding their comorbid psychiatric symptoms. A survey was created to assess affected individuals’ self-reported rates of depression and anxiety, their feelings about the impact of TSC on their lives, their beliefs about the relationship(s) between psychological distress and tuberous sclerosis complex and their satisfaction with their mental health care. 64 individuals completed the survey. Fifty-five (89%) reported a history of either current or past depression and/or anxiety. Of these individuals, only half reported that they had ever discussed their mental health with a medical provider. Mean participant scores on a validated measure of symptoms of depression and anxiety were significantly higher than normative data means. Several associations were identified between participants’ causal attributions and current psychological distress. Associations were also observed between how participants received care (PCP vs. specialty clinic vs. multiple specialists) and how likely they were to have discussed their mental health. Several common themes were noted in participants’ answers to free-response questions including: concerns about passing TSC on to children, difficulties communicating with extended family, issues of independence and how the unpredictability of symptoms impacts where affected individuals work and live.

A better understanding of the impact TSC has on affected people’s lives, patient beliefs about the cause(s) of mental illness and how likely affected individuals are to discuss these issues with their healthcare providers may help us provide better care for this population in the future.

**Supervisory Committee:**
Hope Northrup, M.D., Chair
Syed Hashmi, M.D., Ph.D., M.P.H.
Andrea Harbison, M.S., C.G.C.
Anthony Kerrigan, Ph.D.
Susan Peterson, Ph.D., M.P.H.