Purpose

To improve care coordination, patient and family education, mental health and epilepsy screening, engagement and participation to improve the quality of life of youth with epilepsy.

To test the value of 2 electronically based interventions (Webinars and Facebook epilepsy support group), where patients and families are educated about medical, mental health issues, barriers and important issues that patients with epilepsy face.

To disseminate a bullying prevention intervention for children with epilepsy, which is focused on early screening for epilepsy severity, psychosocial morbidity and quality of life during the epilepsy appointments and during the admissions to the Epileptic Monitoring Unit (EMU).

To educate parents, peers and community about mental health problems in youth with epilepsy.

To empower families to access medical and mental health services for children and adolescents with epilepsy.

To create a Care Coordination program and a Transition Clinic to help decrease the waiting time between when the problem is identified and when the patient actually receives treatment.

To help families to become partners in decision-making about their epilepsy care.

To help assure that the problems involved in the care of the patient, will be aware and engaged on the patient and family needs.

To link all the prevention services needed, all the information relevant for the epilepsy and mental health care and well-being of the patient and family, while providing for transition care at the appropriate time.

Online Support Group

Jane Timmons-Mitchell, Ph.D. & Laura Neece-Balters, MBA

Knowledge Project

Tatiana Falcone, MD, Elisa Pestana-Knight MD

Project CARE 4 Epilepsy

Coordination Access Resources Education 4 Patients with Epilepsy

Cleveland Clinic Department of Psychiatry/ Pediatric Epilepsy Center

Cleveland Clinic

Epilepsy Center

Transition Clinic

Transition Clinic's Goals:

• To help adolescents and their families plan for transition to the adult system of care.

• To ensure appropriate supports are in place to make the patient's overall transition successful.

• To help families become competent in the decision-making process.

• To provide information relevant for epilepsy and mental health care.

• To empower patients and families to become better advocates.

• To assist in the efforts of our Coordination of Care Clinic in ensuring that our patients/ families receive appropriate care within a medical home.

Transition Clinic Overview:

Eligibility: to participates in this program begins at the age of 14.

Families are invited to join a "Journey to Adulthood Nexus", which includes a Transition Planning Guide, Seizure Log, Health Summary, Seizure and Medication Information, Mental/Health Concerns Subscales/TODS use and abuse, and Dating/Peer Relationships and School Supports/Services.

Personalized Assistance, Education, Community Referrals and Personal Goals will help to move them towards independence, as they begin taking more responsibility for meeting your own health care needs.

Local, Ohio and National resources are provided and will help to arm them with the knowledge and support they may need throughout this process.

The patient's last appointment in pediatric epilepsy will include: Pediatric Epileptologist, Adult Epilepsy specialist, Epilepsy Transition Clin, Social Work and Community support personnel(s), when possible.

Enrollment: 7 Evaluated & 22 Feeding appointment

Patient and Family Coordination of Care

Jamelanta John MSW, LSWS

Reasons for the Study:

• To provide education to patients and parents regarding epilepsy and the medications.

• To provide education around the medical and financial/insurance resources that may assist in obtaining additional programs and support in coping with epilepsy.

• To provide referrals to community providers to address issues related to ongoing epilepsy care: a system of care for children, youth, and families affected by epilepsy.

Care Coordination Overview:

Social Work involvement both inpatient and outpatient

Utilize Dr. Connect, Knowledge Project, My Chart

After the initial appointment, a follow-up phone call is set up one month, and contact information is given to parents if they have additional questions.

To provide the opportunity to fill out questionnaires that assist the care coordinator to know what resources are helpful for that person.

The Care Coordination appointments work as a part of a team approach and with the help of the patient help the doctor believes is most effective for each individual's personal care.

Evaluation:

To assess: In the impacted unit, care coordination was provided to 66 families and 15 additional have been assisted with care coordination outpatient.

Mental Health Tool Kit

Tatiana Falcone, MD

Project CARE 4 Epilepsy

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