Knowledge and Access to Care in Families of Youth with Epilepsy on Ohio

Findings from Cleveland Clinic Department of Psychiatry/Pediatric Epilepsy Center (HRSA Project Staff) – permission from Tatiana Falcone, MD

No conflict of interest related to this project.

BACKGROUND

- In Ohio, there are 32,159 youth with epilepsy; the number of Children with Special Health Care Needs (CSHCN) is 570,913. It was estimated that around 227,000 of these children are uninsured.
- CSHCN are a vulnerable population, according to the Ohio Family Health Survey (OFHS). They have greater difficulty accessing the required level of professional mental health services. Overall these patients have higher unmet needs than the general patient population.
- The most important factor enabling access to health care is insurance coverage. In Ohio, children residing in house holds with income less than 200 percent of the federal poverty level are eligible for Medicaid. In 2008, 6.2 percent of CSHCN in Ohio were uninsured.
- According to the OFHS, unmet mental health needs are a greater problem in older children, and the problem becomes worst during the transition to adulthood. Cultural appropriate services continue to be an important area in need of improvement.

Objective:

- To further understand the needs of youth with epilepsy in Ohio. Among youth with epilepsy there are increased mental health needs compared with the general population. They hypothesized that children with epilepsy will have barriers to accessing mental health care and increased educational services.

Methods:

A parent survey was administered to 359 families of children ages 0-18 who were diagnosed with epilepsy.

Surveys were also distributed to epileptologists, school nurses, pediatricians and other key informants.

Methods in detail…

- Needs assessment interviews consisted of data from both focus groups and surveys.
- The surveys results included responses from 359 parents of youth with epilepsy, 6 pediatric epileptologists, 37 school nurses, 7 key informants, 12 pediatricians.
- The key informants; the director of epilepsy association of North East Ohio (NEOH), the past president of the American Academy of Pediatrics, the Title V representative for OH, the director of the Cleveland Clinic Epilepsy Center, a representative from the School Nurses Association of Ohio.
- Two focus groups were conducted with minority families.

Results

Findings about epilepsy and mental health included:

-Access to educational services is a major barrier for youth with epilepsy.

-Parents lack of knowledge about the existing educational services available.

-Poor dissemination of information about the resources for these patients.

-Families (98%) felt empowered and involved in the decision making for epilepsy and mental health services.

-Families and patients (70%) felt they have very little knowledge about epilepsy.

-Most concerns were related to quality of life , poor seizure control and psychiatric co-morbidities.

\N"hat are the principal chaDto accessing health care' "aced by the milies at= children you serve?

A swer Options	Response Percent	ResJ>On.se Count:
tnspo a on	57.7%	15
distance to PCP	30.8%	B
distance t:o spec a l st	26.9 'b	7
locating a sui-table provider	30.8%	a
cos crt medica-ion	61.5%	6
access o med-ea -on	38.59	O
lac of nov.'ledge about: ep1 eps	65.49-b	17
lack of eal1: 1nsurG:nc.e	53.8%	14
ot er no - edical famiy cha-lenges	26.9%	7
other sc cxIJ -rel a:t:ed c a e ges	3.8	1
anSVJered ques -Oiit		.26
skipped question		11.

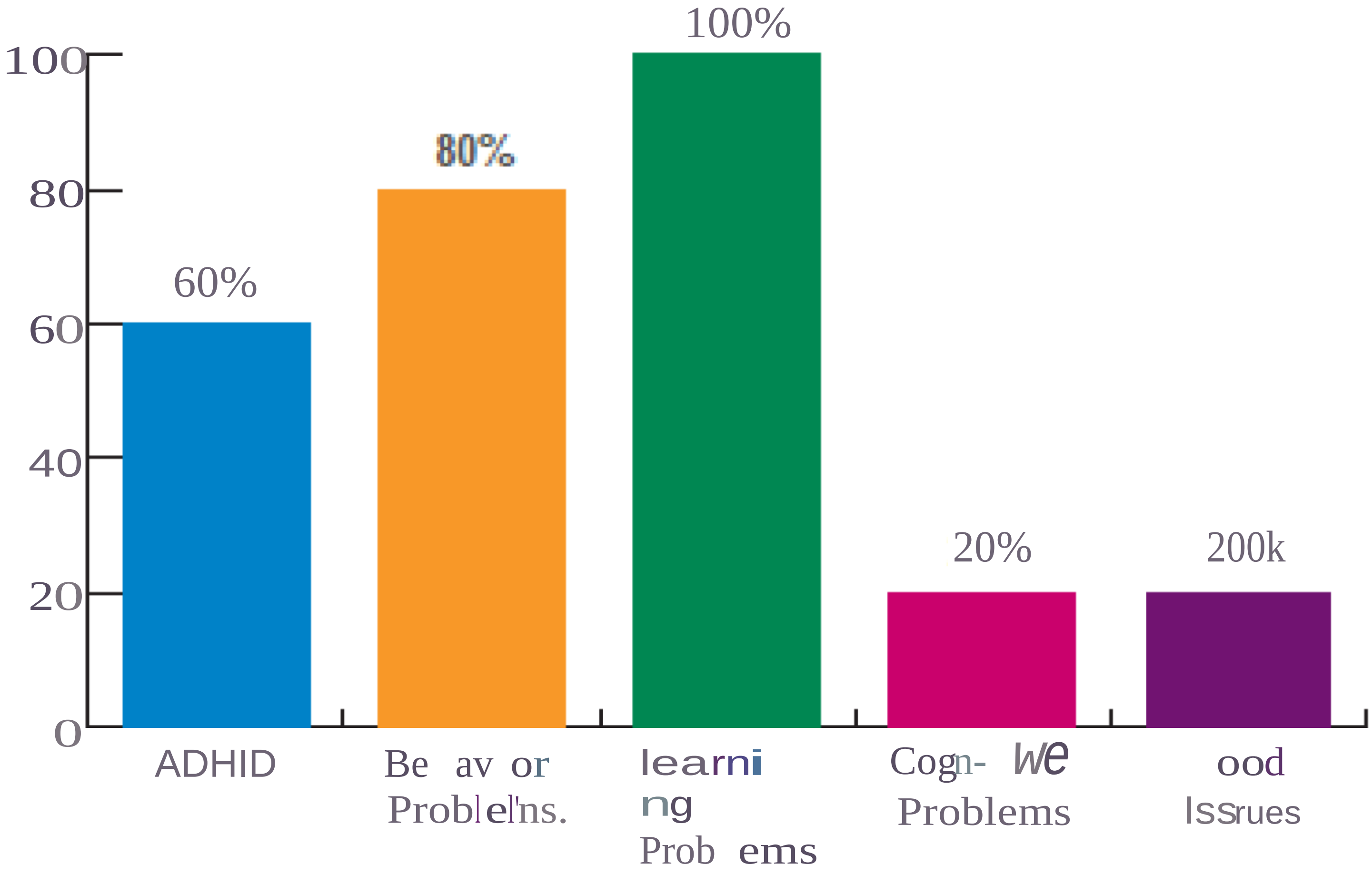
Results, con't…

- Contrary to their belief, most families(76%) felt it was easy to access epilepsy services.
- The wait time for an epilepsy appointment was less than one week for 72% of the families.
- Nearly all (96%; 346/358) of the families had a primary care provider and 58% (187/320) reported receiving care from their PCP at least 2 times a year.
- Almost 92.6 % (327/353) reported receiving care from their PCP at least 2 times a year.

Results, con't…

- Nearly all (98 %; 341/346) families felt empowered and involved in the decision making for mental health services.
- Seventy percent (191/ 274) of their patients felt that they had very knowledge about epilepsy and felt sad, frustrated, overwhelmed when they learned about the diagnosis. Most of the concerns were related to quality of life, poor seizure control and psychiatric co-morbidities.
- Families (73%; 198/270) felt that they were given information about epilepsy, epilepsy and psychiatric co-morbidities mostly by the specialist (pediatric epileptologist, child psychiatrist).
- Pediatricians in the Cleveland community felt that epileptologists provided most of the epilepsy care and child psychiatrist provided most of the mental health care for youth with epilepsy.
- Epileptologist, Child psychiatrist and PCP's identified reimbursement as a barrier for epilepsy and mental health care for youth with epilepsy for as many as 75% of their patients.

Epileptologist identified the comorbidities as follows:



Conclusion

- There are important and under-recognized unmet needs in youth with epilepsy.
- Psycho-educational is a key piece to help families of youth with epilepsy to cope with some of the co-morbidities these patients face.
- Although many services are provided in their community, parents and children do not know about these services and do not access them.
- It is important to engage PCP’s in the psycho-educational piece of youth with epilepsy.
- Stigma continues to be an important barrier for patients and families in accessing mental health services.
- Educating first responders (school nurses, parents, pediatricians), will help us decrease stigma and will improve access to mental health services by youth with epilepsy.

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