Barriers to Transition to Adulthood for People with Dravet Syndrome

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Introduction

Many caregivers of patients with genetic epilepsy report problematic transitions to adult care, often returning to pediatric providers and relying on emergency departments for care. Without consistent and appropriate medical supervision, epilepsy becomes more difficult to control. Uncontrolled epilepsy can lead to poor outcomes including sudden unexplained death in epilepsy (SUDEP) and increased rates of behavioral and cognitive problems (Devinsky, 2014).

Caregivers of children with genetic epilepsy report similar difficulties with transitioning to community-based programs after high school graduation.

Devinsky, O. (2014). Transition to adult care for children with epilepsy--a call for action. Epilepsia, 3, 54-5.

Objectives

The goal of the Genetic Epilepsy Transition Study (GETS) is to characterize the transition experiences and related recommendations of caregivers of teenage and adult patients with genetic epilepsy.

Materials and Methods

We obtained an IRB exemption determination before seeking informed consent from 18 caregivers of teenagers and adults with Dravet syndrome (DS).

We conducted a three-week, asynchronous, web-based focus group to ascertain participants' experiences with the transition process and brainstorm factors for success and failure.

Data were analyzed and theories constructed using the Grounded Theory approach.

Results

"Something happening to my husband and myself, leaving us unable to care for him is BY FAR my greatest worry."

-Participant and mother of individual with Dravet syndrome

Table 1
Participant Characteristics
N=18

		Range	Mean
Age of Affected Individual		13-33	22
		N	**%**
Caregiver Gender	Female	18	100
	Male	0	0
Geographic location	Rural	2	11
	Urban	4	22
	Suburban	12	67
Neurologist	Pediatric (patient is a child)	4	22
	Pediatric (patient is an adult)*	10	56
	Adult	4	22

***71% of adult individuals are still seen by a pediatric neurologist.**

"…they are pretty intimidated... If he is lucid, they are frequently asking him questions that are outside of his realm of understanding."

-Participant and mother of individual with Dravet syndrome

CAREGIVERS START THINKING ABOUT TRANSITION AT DIAGNOSIS.

CLINICAL and COMMUNITY transition are intertwined.

Definition of success: how well transition addressed the caregiver's "greatest fear": adequate care for their child when the caregiver is unable to care for them.

Clinical, all settings and specialties:
- **Lack of knowledge of DS**: contraindications and comorbidities.
- **Discomfort with adults with intellectual disabilities, challenging behaviors.**
- Adult clinicians **dismissive of caregiver knowledge** of DS.

Community:
- Inexperience with individuals with uncontrolled seizures, severe and challenging behaviors
- Cognitive functional level too high or low for program requirements
- Support worker shortage
- Barriers to access due to rural health disparities
- Threats to caregiver work/life balance

Caregiver recommendations

- Start transition BEFORE adolescence.
- Create "Transition Navigator" role.
- Increase educational and advocacy opportunities for adult neurologists on DS and other genetic epilepsies.
- Provide early, comprehensive, and state-specific caregiver education.
- Develop multidisciplinary transition team.
- Design research on long-term outcomes for adults with DS.