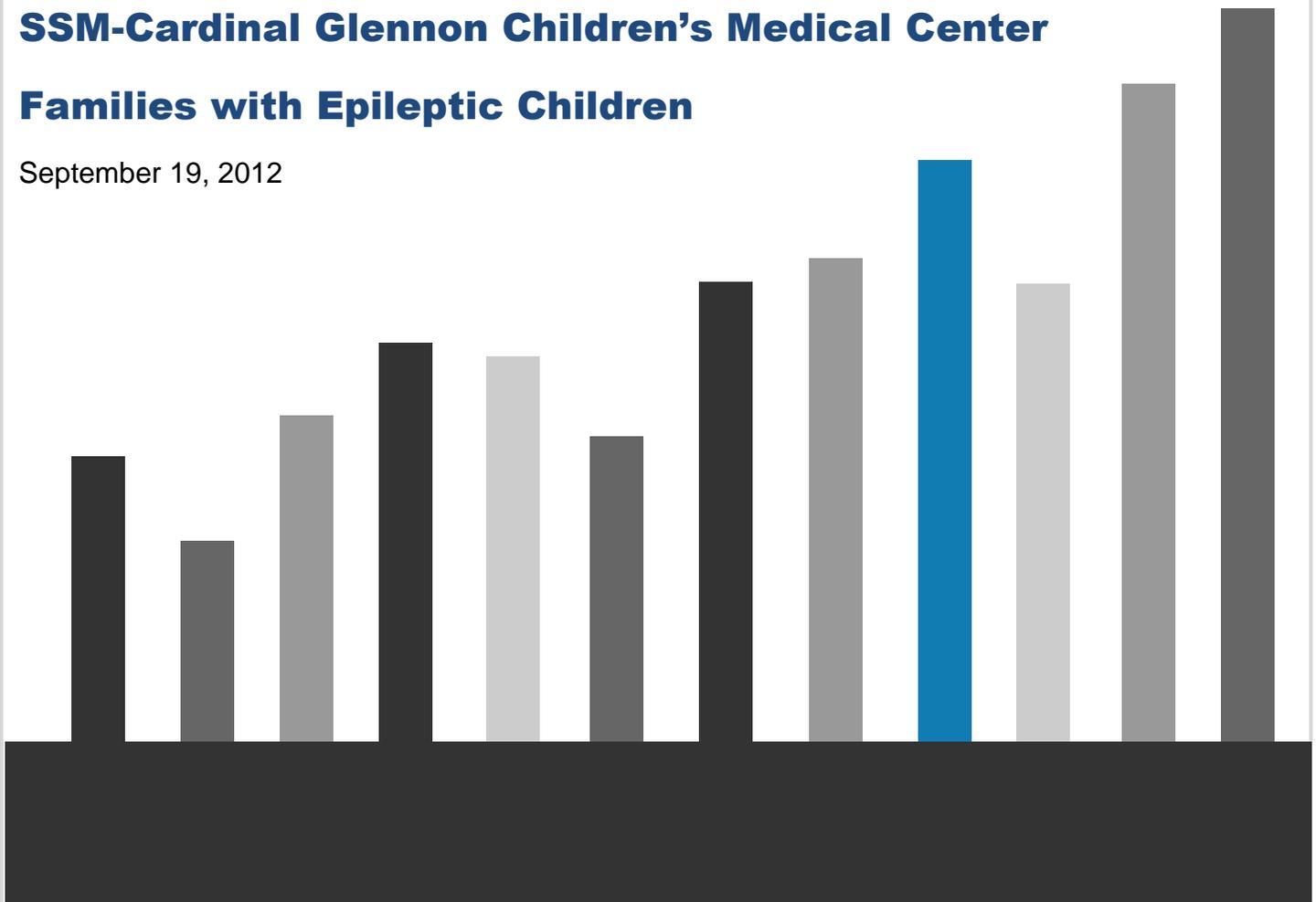


SSM-Cardinal Glennon Children's Medical Center

Families with Epileptic Children

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Research Development

Research Design and Objectives

This research is guided by three research objectives (RO), each with several associated research questions (RQ). A matrix explaining how these questions and objectives shaped the survey design is included in Appendix A on page 16.

Objectives

RO1: Diagnosis of Epilepsy

Develop an understanding of how families experience the epilepsy diagnosis process and what health care service providers could be doing to better equip and prepare families for their child's plan of care.

Questions

RQ1.1: What concerns and surprises did families experience during the diagnosis process?

RQ1.2: How have families found that raising an epileptic child differs from raising other children?

RQ1.3: What information would have helped families through the process?

RQ1.4: How did families respond to the diagnosis?

RQ1.5: How could families have been better prepared for their child's plan of care?

RO2: Support Service Assessment

Develop an understanding of the educational and emotional needs of families with children who have been diagnosed with epilepsy, of the support services that they have made use of (whether from CGCMC or outside agencies), and how these services can better meet their needs.

RQ2.1: How could educational support services for the parents and for the children who have been diagnosed with epilepsy be improved?

RQ2.2: What resources do parents and children appreciate, and what do they find lacking?

RQ2.3: What support services do families find the most and least helpful?

RQ2.4: What additional support services do families feel are needed?

RQ2.5: Where can existing support services be improved to better meet the needs of families?

Research Development

Research Design and Objectives

RO3: Transition to Adult Care

Develop an understanding of how families with epileptic children transition from pediatric care to adult care and identify where there may be problems in the process.

RQ3.1: How do parents and children perceive the transition from pediatric care to adult care?

RQ3.2: What advice would those families who have been through the transition offer to those who have not yet been through it?

RQ3.3: Where can the needs of families making this transition be better addressed?

Research Development

Research Methodology and Sample

Population

The population is defined as parents who are primary caretakers of children who have been diagnosed with epilepsy or are prone to seizures and who have been patients at CGCMC, or children aged 14 to 21 who were previously diagnosed with epilepsy or are prone to seizures and who have been patients at CGCMC.

Sample

The sample for the population was drawn randomly from a list of phone numbers a list provided to RPG by Cardinal Glennon that included patient contact numbers and information.

Potential participants were mailed a letter from CGCMC notifying them about the study. This letter included information on how they could opt in or out of the study if they wished.

Methodology

This study was primarily conducted through a two-part series of individual telephone in-depth interviews (IDIs) conducted with patient families of CGCMC in St. Louis and the surrounding area. One set of telephone interviews was conducted with parents of a child who had been diagnosed with epilepsy.

The second set of telephone interviews was conducted with children aged 14 to 21 who have been diagnosed with epilepsy. Interviews lasted between 30 to 60 minutes.

The study included the following groups:

- **Recent diagnosis:** 16 families where the child has received a diagnosis within the last three years.
- **Transition:** 10 families where the child is old enough to have begun or completed the transition from pediatric care to adult care.
- **Child:** 5 patients aged 14 to 21 who were previously diagnosed with epilepsy or who are prone to seizures.

Each interview included a section where the family or child was asked to identify educational resources the family has made use of and then to provide satisfaction ratings of each resource on a scale of 1 to 5.

Patient families were also asked several questions about the diagnosis process as well as their preparedness for the transition from pediatric care to adult care.

The data collection for this study was conducted during the month of August with 26 families and 5 children. In total, 31 interviews were conducted with patient families.

Research Development

Research Analysis and Limitations

Analysis

The research team went through the data set using a thorough categorization process.

For **open-ended** data, RPG examined each question's responses and developed a categorization system. Categories are presented in terms of the frequency counts in which a theme arose.

Since many responses included multiple categories, responses were often split to allow for a more precise understanding of which themes were most common. This is indicated by the tag [split] at the end of some respondent comments.

Because the **scaled** questions pertaining to support services yielded little useful data, the frequency counts of each scaled question are included in the appendix, but were found to have little influence on the key findings.

Limitations

The data gathered in this study is **qualitative** and the findings should be viewed as being **directional** in nature.

The data should not be used to assess CGCMC's performance in serving families of children with epilepsy and should only be used to assess where deficiencies of service may be present.

Due to the small sample size, the results should not be projected to the population as a whole, nor should they be projected to families of children who have been patients at a hospital other than CGCMC.

Key Findings

R01: Diagnosis of Epilepsy

Parents and children were asked to discuss their reactions to the initial diagnosis of epilepsy and to describe how they could have been better prepared for that diagnosis.

Findings

Respondents in this study included patients with a range of circumstances and diagnosis, from a single seizure episode to chronic seizure episodes. Often, a child’s epilepsy diagnosis was one of many medical diagnoses. Despite the high amount of variation within the sample, a theme emerged around the challenges of everyday parenting while simultaneously trying to understand the multiple layers of a complex medical condition.

Many parents said there was no way to truly prepare for their child being diagnosed with epilepsy. While the diagnosis itself was a shock to some families, most families felt their physician explained the diagnosis in a way that was easy to understand and thorough.

Upon receiving the initial diagnosis parents expressed an array of emotions – fear, uncertainty, apprehension and relief. For parents unfamiliar with epilepsy, watching their child have a seizure the first time was a terrifying experience. This was especially true for those who had to take their child to the emergency room because of the seizure. Several parents articulated the anxiety they experienced waiting to see a neurologist at CGCMC.

Those who were not fearful or apprehensive of the diagnosis often had a family history of epilepsy. These parents described their initial reaction calmly. They were not surprised by the diagnosis and some even expected it. A few families felt relieved by the diagnosis because they finally had an answer to what had previously been a mysterious medical condition.

How to Better Prepare for the Diagnosis

Thematic Category	Count
There is no way to prepare	9
More information	7
Don't know	6
I couldn't have been better prepared	4
Classes or support group	3
Earlier detection and clearer answers	3
We knew it was a possibility but didn't believe it would happen	1

Response to Diagnosis

Thematic Category	Count
Scared	10
Uncertainty	8
Not shocked/Expected	7
Upset/Sad/Traumatic	6
Concerned/Nervous	5
Shocked	3
Relieved	2
Other	5

Key Findings

R01: Diagnosis of Epilepsy

Parents and children were asked to discuss the concerns and surprises they encountered following the child's epilepsy diagnosis.

Findings

Even though most families felt their physician did a good job of explaining the diagnosis, many expressed they would have felt better prepared had they been given more information at the time of the initial diagnosis.

Parents expressed a desire to have more knowledge about the triggers and causes of seizures and how to prevent a seizure from happening in the future. Some parents would have liked to receive more information regarding the anti-seizure medications and its side effects.

Looking beyond specific medical information, parents would have also liked to learn more about the how their child's condition may impact his or her future opportunities.

Many parental concerns were about the safety and well-being of their children. Parents felt they needed to be more cautious and monitor their child with epilepsy more than other children. Areas parents paid particular attention to were **administering medication, identifying triggers** and **limiting activities** that would be unsafe for a child prone to seizures.

Most parents did not feel that they needed to adjust their parenting philosophy to suit the needs of their child with epilepsy, and tended to think of their child as being no different from children without an epilepsy diagnosis. This was true even for those whose children had special needs coupled with an epilepsy diagnosis.

After the initial diagnosis, the surprises most parents encountered were pleasant. Many parents saw their children respond to the disorder with resilience. The children did not seem to feel held back by the diagnosis, but flourished in spite of it. Some parents, however, felt taken aback by the reactions of other people and felt they were labeling their child as different even though they did not feel their child deserved this label.

Desired Information at Diagnosis

Thematic Category	Count
Causes and triggers	8
Signs of epilepsy and seizures	5
How condition might progress and impact my child	4
Medications and side effects	3
Seizures connection with other diagnoses	3
More information geared to my child's age	2
Support services	2
Other	4

Concerns Regarding Epilepsy

Thematic Category	Count
A seizure causing serious or further injury	7
Driving and other activities	7
My child will be alone or not with me during a seizure	7
My child's future outcomes	6
Medication	5
No concerns	4
Physical and mental changes	4
Seizures will happen again	3
Seizure condition will become worse	2
Medical care	1

Surprises Encountered with Epilepsy

Thematic Category	Count
My child's resilience and accomplishments	9
Nothing surprising	7
Diagnosis itself	6
Others' reactions	6
Medication's effectiveness and side effects	3
Not knowing cause or how to stop seizures	2
Other	4

Key Findings

R01: Diagnosis of Epilepsy

Respondent Statements

It was scary, and I just wanted to know why and what caused it. I immediately went to figure out why and what caused the seizure.

-Recent Diagnosis

I wish I had heard more about it and had more information. I have heard of epilepsy as a whole but didn't know subcategories and all that kind of stuff. Cardinal Glennon gave me literature, but I wish there was more in-depth information on different kinds of epilepsy.

-Recent Diagnosis

Oh my goodness. I freaked out until I spoke to the doctor.

-Recent Diagnosis

The biggest thing I remember was the helplessness, because there was nothing we could do to make it better for him. We also questioned ourselves—was there was anything we did to cause it?

-Transition

I was upset, but there is nothing much you can do. They have medicine to help him. We had a friend who's kid had epilepsy, and they didn't give him meds and he ended up dying.

-Transition

At first, I was scared because I didn't know what he was doing. Then when they explained it, I was more accepting of it because they explained it to me well.

-Transition

Conclusions

Having a child diagnosed with epilepsy is a challenging time for parents. From witnessing their child's first seizure to receiving the diagnosis, parents are scared and oftentimes shocked. Physicians at CGCMC do a good job of communicating to parents the intricacies of the medical condition in a way that is understandable and thorough. Just by giving parents information about medication and seizure triggers, physicians are able to quell some of the apprehension about having a child with epilepsy.

The official epilepsy diagnosis is the first step in a complex medical journey with their child. Raising a child with epilepsy brings its own unique hurdles. Parents are more aware of their child's behavior and are vigilant about administering medication. Looking toward their child's future, parents feel concerned about their child living a full, unrestricted life. Parents worry about their child being able to drive, play team sports, and experience other coming of age activities.

For parents, the bright side of raising a child with epilepsy is witnessing the resilience of their child. Parents see their children take the diagnosis in stride and continue living life to the fullest. Seeing their children overcome the obstacles associated with a chronic medical condition by accomplishing things beyond what the doctors thought possible is surprising and rewarding.

Key Findings

RO2: Support Service Assessment

Parents and children were asked to discuss what support services they have used and what support services have been the most helpful to them.

Findings

There appears to be a significant gap in what support services parents would like to have available and what services are offered. Many families were unaware that there were support services available to them and were unsure of how to access those that did exist. Families communicated a need for two types of support services: those that inform and educate and those that provide emotional support.

After gathering information from CGCMC and its physicians at the time of diagnosis, families often turned to the pamphlets distributed by their physician or to the internet for any additional informational needs.

Parents tended to consult the internet when questions arose about their child’s condition, but their internet information search did not always provide answers, and in some cases added to their uncertainty. After encountering conflicting information online, some parents had even more questions about their child’s condition. For this reason, parents used the internet to develop their questions and followed up with their physician to clarify their questions.

Parents acknowledged that CGCMC and their children’s physicians act as a primary source of information. When asked what organizations aside from CGCMC and their child’s physician they had made use of, most parents said they had not sought support elsewhere.

Educational Resources Used

Thematic Category	Count
None	20
Internet	15
School district programs	13
No resources offered	13
Community resources/Social workers	6
Pamphlets/Books	6
Friends/Family	2
Physician	2
Other	4

Resources Used (Outside of child’s physician and CGCMC)

Thematic Category	Count
None	23
Physician	4
Community organization	2
I didn’t know there were any	2
Internet	2
My social circle	2

Helpfulness of Support Services

Thematic Category	Count
We haven’t used support services	12
Not helpful because we had no support services	7
They were informative about my child’s condition	4
They were there when I needed them	4
They helped me find additional resources	2
Other	3

Key Findings

RO2: Support Service Assessment

Parents and children were asked to identify the resources they have used and appreciated most and to identify the resources they found disappointing. They were also asked to offer advice to a hypothetical, newly forming organization that will help families of children with epilepsy.

Findings

When asked what resources they appreciated most, parents and children most often mentioned CGCMC physicians and staff, followed by pamphlets, brochures, and the internet. Families also expressed an appreciation for community resources provided through independent organizations and public schools.

Many parents indicated they had not been disappointed by **any** resources. Others did not know because they had not had enough interaction with support services to provide an assessment.

At the same time, many parents simply did not know what support services were available. Making resources known to parents was the most commonly mentioned way to improve support services. Parents suggested having a centralized place where they can access a listing of all available support services. Some parents would prefer to have this information on a website while others would like it as a pamphlet. Others felt that having a support group comprised of parents would offer a way for parents to exchange information about helpful resources.

When offering advice to a new organization that would help families of children with epilepsy, parents advised offering support groups for both parents and children. Parents who suggested supports groups saw them as a source of comfort and emotional support as well as a place to learn practical strategies for raising a child with epilepsy. Other suggestions for a new organization were to provide information and classes about living with epilepsy as well as creating a centralized place find this information.

Most Appreciated Resources

Thematic Category	Count
CGCMC staff/child's physician	35
Internet	10
Community resources – schools and other organizations	8
Brochures and pamphlets	6
None/don't know	5
My mom/grandmother	4
Other	6

This chart contains information from two related questions.

Desired Support Services

Thematic Category	Count
Don't know/None	10
A support group	7
Information from families with epileptic children	6
Centralized source of available resources	5
A support line	4
More information and training	4
Social opportunities	4
Financial assistance	2
Other	3

Suggestions for a New Organization

Thematic Category	Count
We need a support group	14
We need a variety of information	10
We need a centralized place for information	8
We need classes and training	6
We need social opportunities for our children	6
We need a call line	4
Don't know	3
We need respite	3
Our children need age appropriate information	2
Other	7

Key Findings

RO2: Support Service Assessment

Respondent Statements

It would have been nice to also get information from someone not in the medical profession. For instance, my daughter did not take her medicine, so it would have been nice to hear from a parent about what they did.

-Transition

Because I wasn't aware of any, not helpful at all. I didn't have anything that said go here, you can learn something.

-Recent Diagnosis

A directory that has phone listings of things in your community you can use as resources. For instance, if you lived in St. Charles County, the directory would tell a parent they could go here and here. As a parent, I went and sought out playgrounds that were kid friendly and designed for individuals who have higher needs than the average child. Someplace a parent can go to that has a master list of community resources and answer questions.

-Recent Diagnosis

I think they should start a support group.

-Recent Diagnosis

He went for a year without having a medical alert bracelet. It never crossed my mind to have one. We were talking with one of our friends whose son also had seizures and realized we needed one as well.

-Transition

A help hotline for parents who are having trouble dealing with this or maybe just need an outlet. We just need support in this situation.

-Recent Diagnosis

Conclusions

Families of children with epilepsy have a need for informational and emotional support and feel that need is not being met. For the most part, parents are unable to identify support services, outside of CGCMC, that are available to them.

Parents informational needs continue past the point of diagnosis. While epilepsy-specific information provided at the time of diagnosis and during doctor's appointments is useful, it is not enough. After consulting the internet for additional information about their child's condition, some parents are left with more questions than answers.

The emotional needs of families with children who have epilepsy are greatly underserved. Parents would like to see support groups for themselves and their children as a means for exchanging information as well as for offering emotional support to one another. The challenges of raising a child with epilepsy are best handled by finding comfort in knowing other families have similar experiences.

Parents suggest offering a centralized source that contains trustworthy information about epilepsy and any support services available to families raising a child with the condition.

Since parents did not seem to be aware of any support services outside of their child's physician, it is important for physicians to help connect parents with external support services by providing a resource list.

Key Findings

RO3: Transition to Adult Care

Families and children were asked to discuss the transition into adult care and what support services outside organizations could offer to children transitioning to adult care.

Findings

Parents of children who have not yet made the transition into adult care often had not thought about the transition because their children were too young to consider that far into the future. Parents of these younger children were focused on raising their child on a day-to-day basis and managing the demands of the seizure disorder in the present moment. Some parents felt worried or concerned about the transition because they did not want seizures to limit their child’s future. Other parents felt they would be ready for the transition as long as their child’s pediatrician guided them through it.

For the most part, parents with children who have made the transition to adult care said that it went well. For some children, this was a time when they were taken off their daily medication and for others it just meant switching physicians. Some parents and children were scared of the transition and felt nervous to see a new physician after having developed a long relationship with a CGCMC physician. Some families felt let down by the transition and did not feel as supported by their new physician as they had at CGCMC. For both the parents and children, the most difficult part of the transition was the sadness about leaving CGCMC.

Many parents felt their child’s physician could better prepare them for the transition by keeping them informed throughout the process. Additionally, parents articulated a need for their child’s physician to provide them with referrals to adult care physicians and to act as a liaison between themselves and the child’s new physician.

When asked what types of support services outside organizations could offer to help families go through this transition, parents requested education and guidance. They would like to know what to expect and how to navigate switching from pediatric to adult care.

Parents also saw a need for support groups during this transition. They felt this would give their children the ability to connect with a peer who was going through or had been through a similar circumstance.

Families who had made the transition to adult care were asked to offer advice to families who were about to go through the transition. For families who had been through the transition, finding a doctor they could trust and who was a good match for their child was the most commonly-offered piece of advice.

Readiness for Transitioning to Adult Care

Thematic Category	Count
I am not ready	5
I am ready	5
I haven’t thought about it	3
It scares/concerns me to think about it	3
With preparation, I will be ready	3
Other	2

Note: This question was only asked of those families who had not yet made a transition to adult care.

Preparation from Physician

Thematic Category	Count
Keep me informed	12
Provide me with resources and referrals	10
Unsure/No advice	5
No need to prepare	2
Provide my child’s information to his new doctor	2
Give my child more control over his medication	1
Listen to my child	1

Preparation from External Organizations

Thematic Category	Count
Education and guidance	13
Don’t know/None	12
Support groups for me or my child	5
Other	5

Key Findings

R03: Transition to Adult Care

Respondent Statements

He is off his meds now and seizure free. It was exciting for us...There was absolutely nothing negative about that transition. He was so much more awake and alert. Everything was positive for us.

-Transition

My main question is whether his doctor will know as much as his pediatrician.

-Recent Diagnosis

His doctor could educate him on triggers and things he needs to avoid in order to prevent seizures. He would be able to be informed about his condition.

-Recent Diagnosis

When that time comes, I think with the guidance of the medical staff, he will be ready.

-Recent Diagnosis

It was hard because we really liked Cardinal [Glennon], and everybody knew us and had all his information. I do love the doctor, and its closer, but it is just different.

-Transition

Find the doctor that suits your child, and don't settle for a doctor they give you if he is not a good a fit.

-Transition

It was scary. I didn't want to leave Dr. Fenton. He had always been at Cardinal [Glennon]. Then you worry, if something bad happens, who should I call?

-Transition

Conclusions

The transition from pediatric care to adult care is not a process that constantly preoccupies the thoughts of families with children who are epileptic. More focused on the routine and demands of daily life, most families have not thought that far ahead. Some parents voiced concerns about whether or not their child would have enough opportunities in the future regarding jobs and general well-being; these concerns about the transition to adulthood were associated with the transition to adult care.

Those who had already gone through the transition felt like it was a fairly smooth process. Some families expressed sadness about leaving a pediatrician they felt close and familiar with and were somewhat hesitant about meeting a new physician.

The needs of the families making the transition to adult care exist throughout and beyond the just a change of doctors. Parents wish to be kept informed and educated, as well as be guided through the transition, whether by their child's pediatrician or outside organizations.

Many suggested offering support groups, mostly for the child's emotional benefit. Families would also like any questions they have about the transition to be answered by their pediatrician. These include questions the child has about his or her condition as they enter adulthood, in addition to questions about future opportunities. Parents and children alike see their doctor or hospital as a source for advice on many aspects of an epileptic patient's adult life.

Families who had gone through the transition noted that finding a physician the family can trust and is comfortable with makes the transition easier. It's important to these families to feel a close bond with their doctor.

Conclusions

General Conclusions

Diagnosis of Epilepsy

Once a child receives an epilepsy diagnosis, families are confronted with a mix of emotions that are quelled by receiving information about the condition from the child's physician.

A parent's concern for his or her child reaches beyond the fear of seizures and encompasses an apprehension about the child's future possibilities and limitations. Yet, parents are surprised to see how their children flourish in spite of a chronic, sometimes debilitating, medical condition.

Support Service Assessment

Parents of children with epilepsy have a need for support services, but are unaware of how to access them and are often uncertain if those services even exist.

The support services that are available to parents are viewed positively, but they are not meeting all of the needs that parents have. Parents would like better access to on-demand informational resources, perhaps through a dedicated website or telephone hotline.

Parents would also like to have a single resource list that they can refer to when looking for support and information from an external organization.

Parents rely on CGCMC physicians and staff to be information providers but would like to receive advice from and collaborate with other families through support groups for both parents and children.

Transition to Adult Care

The transition to adult care is not something families generally think about until it is time to make the transition. Parents of young children with epilepsy, in particular, are focused on the day-to-day interactions with their child rather than their child's long term care.

When it is time to make the transition, families and children find the transition overwhelming and saddening because they are leaving the safety and familiarity of CGCMC.

Preparing for the transition to adult care requires being informed throughout the process and acquiring referrals to adult care physicians from the child's pediatrician.

Conclusions and Recommendations

Next Steps

Share Results with Potential Participants

The research team recommends sending a letter to all potential participants for this study thanking them for willingness to participate and sharing some selected findings derived from the study. It is also recommended that CGCMC share with them some of the actions that it plans to take as a result of this information.

Sharing this information with families will help to reassure them that their opinions have been heard and taken seriously. It will also foster a spirit of openness and transparency that will help shape a positive view of CGCMC and the support services that it will be offering in the future.

RPG is happy to provide any needed input into the crafting of such a letter.

Share Results with Physicians

The research teams recommends sharing this full report with physicians that work directly with families who have children with epilepsy.

This will help the physicians to foster a sense of pride in the great work they are already doing and reinforce the importance of creating a culture of information sharing with families of children with epilepsy.

It will also help them to better understand the challenges that families are facing, but which they might not communicate as clearly when interacting with their physicians.

Conducting Brainstorming Groups

The research team recommends conducting brainstorming groups with parents of children with epilepsy. Each group could include around 6-8 families who have children of a similar age or of similar medical conditions.

These focus groups would not need to be treated as formal research, and could be administered by a member of the CGCMC staff rather than a professional researcher. The moderator's guide for these groups could be intentionally unstructured, focusing on a few of the findings of this study, but largely leaving things up to the participants to discuss among themselves.

The purpose of these groups would be to bring families together, allow them to have a group discussion about their ideas for support services, and to allow them to share their stories with one another.

Brainstorming groups would allow families to creatively design support services that would best serve their unique needs. The groups would also act as a form of support for families by giving them an opportunity to share their experiences and techniques for living with a child who has epilepsy.

Additionally, because families expressed a tremendous need to collaborate with one another for support as well as information sharing, these brainstorming focus groups could be the launchpad for more formal support groups.

RPG is available to assist in the design and administration of these groups, as needed.