

National Coordinating Center for Epilepsy

CYE Needs Assessment Report

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Executive Summary

Overview

The American Academy of Pediatrics (AAP) serves as the National Coordinating Center for Epilepsy (Center) through a cooperative agreement with the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB). The Center supports professionals working to improve access to coordinated, comprehensive, and quality care for children and youth with epilepsy (CYE). As part of the current *Innovations in Access to Care for Children and Youth with Epilepsy* project, the Center was tasked with conducting a national needs assessment. The needs assessment sought to determine the perception of existing gaps and challenges in health care for CYE, along with the assets, resources, capabilities, and strengths that patients, their families, and health care providers possess. This executive summary presents methodology, high-level results, and recommendations.

Methods

Center staff utilized a mixed methods approach to conduct the needs assessment between March and June 2021. Quantitative data was collected through anonymous SurveyMonkey questionnaires. Focus groups and key informant interviews were conducted virtually via Zoom by Center staff. Participants were recruited through a variety of internal and external channels, including AAP News OnCall, various social media platforms, and stakeholder/partner promotional efforts. Participants included parents/caregivers of children and youth with epilepsy (CYE) (n=337), young adults living with epilepsy (n=116), health care providers (n=40), and CYE Advisory Committee members (n=9).

Results

Demographics

- Most parents/caregivers identified as being White, non-Hispanic (63.2%) and reported having private insurance (60.7%). A plurality reported living in a suburban setting (45.7%) and having their child's epilepsy diagnosis occur more than three years ago (37.7%).
- The majority of young adult respondents identified as White, non-Hispanic (72.7%), had private insurance (55.5%), and reported that their epilepsy was diagnosed more than three years ago (75.5%). A plurality was between 20 and 24 years of age (42.7%) and lived in the suburbs (48.2%).
- Most AAP member survey respondents were medical doctors (71.0%). The respondents were nearly evenly split between primary care (51.6%) and neurology (48.4%), and most provided care exclusively to pediatric patients (74.2%).

Access to Care

- When evaluating different aspects of access to care, parents/caregivers rated getting “necessary care, tests, and treatments” from their medical team most favorably and being able to “schedule an appointment with a specialist” least favorably. Access to care barriers experienced by parents/caregivers of CYE included lack of access to specialty care, not being taken seriously by primary care and specialty care providers, and difficulty accessing the provider directly.
- Young adults rated being able to “schedule an appointment for illness/injury as soon as needed” most favorably and getting “necessary care, tests, and treatments” least favorably. Young adults stated feeling like the “doctor did not respect me;” lack of trust/connection with doctor; and having to change doctors multiple times before finding one whom the young adult felt understood/respected them.
- Access to care barriers noted by health care providers and stakeholders included geographic/transportation-related barriers for patients and families, capacity-related barriers, and patient-related barriers.

Telehealth

- More than half of parents/caregivers (55.20%) cited being seen/having their questions answered sooner as a major benefit of telehealth. Other key telehealth benefits for parents/caregivers included having their child miss fewer school hours (46.2%), missing fewer work hours (45.2%), and feeling less stressed/burdened (44.8%). For appointment preference among parents/caregivers, 41.6% preferred telehealth visits, 42.5% preferred in-person visits, and 16.0% had no preference. Overall parent/caregiver experiences with telehealth were positive, comfortable, and convenient.
- More than half of young adult respondents (56.30%) cited being seen/having their questions answered sooner as a major benefit of telehealth. Other key telehealth benefits for young adults included fewer out of pocket expenses (40.6%), feeling less stressed/burdened (34.4%), and missing fewer work hours (31.3%). For appointment preference among young adult respondents, only 24.6% preferred telehealth visits, while 64.6% preferred in-person visits, and 10.8% had no preference. Most young adults reported that they prefer in-person appointments, but they also acknowledged that telehealth is easier and more efficient.
- When asked about telehealth barriers and benefits, half of the AAP member respondents (50.0%) cited patient technology as a major barrier to telehealth. Perceived minor barriers included clinic technology (59.1%), patient preferences (59.1%), and cultural and language barriers (54.6%). Benefits of telehealth include eliminating the need for patients to travel and enabling providers to see patients in their home environment.

Quality of Care

- While parents/caregivers generally perceived quality of care favorably, their experiences with seizure action plans were less positive than overall health care, primary care, and specialty care. The most significant quality of care issue raised by parents/caregivers was not being respected and not being taken seriously by the provider.
- Overall, young adults rated quality of care less favorably than did parent/caregiver respondents. Of all quality of care items assessed, experiences with seizure action plans were rated least favorably. Young adults reiterated that not being respected and not being taken seriously by the provider was their most pressing quality of care concern.
- Health care providers and CYE Advisory Committee members indicated that the best way to impact quality of care is to improve primary care provider (PCP) ability to diagnose and treat epilepsy. When asked a series of knowledge and confidence questions, PCPs were most knowledgeable about knowing when to refer to a specialist and least knowledgeable about creating a health care transition office policy. Similarly, PCPs were most confident about knowing when to refer patients with epilepsy to a specialist and least confident about managing side effects of medications for CYE.

Shared Decision-making

- For parents/caregivers, shared decision-making (SDM) was positively correlated with perceptions of access to care and perceptions of quality of care. Parents/caregivers who reported positive perceptions of SDM also reported feeling less negative about their child's epilepsy. Barriers to successful SDM included ineffective communication from providers and not receiving adequate information and resources, particularly at the time of diagnosis. To improve SDM, parents/caregivers suggested having health care providers complete trainings to improve their communication skills, specifically being able to provide information in lay language.
- For young adults, SDM was positively correlated with perceptions of access to care, perceptions of quality of care, and perceptions of telehealth. Young adults who reported positive perceptions of SDM also reported feeling less negative about their epilepsy. Young adults' suggestions for improving SDM included having the provider share more information about treatment options, medications, and sudden, unexpected death in epilepsy (SUDEP) during appointments. Young adults also emphasized wanting to be treated holistically.

Communication and Care Coordination

- Parents/caregivers of CYE reported a lack of communication and sharing of information between PCPs and specialists. Parents/caregivers felt like time was wasted repeating information during appointments that was already in the medical records.

- Communication and care coordination between primary care providers (PCPs) and specialists are critical components of overall health care for children and youth with epilepsy (CYE). While specialists rated their communication with PCPs more favorably than PCPs perceived it, both PCPs and specialists acknowledged that care for CYE was not well coordinated. A frequently cited barrier to care coordination was disparate electronic health record (EHR) systems. Lack of time to engage in meaningful care coordination and limited compensation for time spent communicating with each other were also cited as care coordinating pain points.

Recommendations and Conclusion

The needs assessment utilized a mixed methods approach to collect a great deal of data from parents and caregivers of children and youth with epilepsy, young adults living with epilepsy, primary care and specialty care physicians, and additional stakeholders. This information presents opportunities for the National Coordinating Center for Epilepsy and its national partners to take concrete steps to improve access to coordinated, comprehensive, and quality care for children and youth with epilepsy. Based on a strategic planning session with its CYE Advisory Committee in August 2021, Center staff drafted a list of recommendations for both the Center and the field of pediatric epilepsy on the following domains: resource dissemination; education; partnerships; promoting health equity and culturally competent care; addressing system-level issues; and research. These recommendations will be refined into a strategic agenda for the Center and the field of pediatric epilepsy care to support professionals and families working to improve access to coordinated, comprehensive, and quality care for children and youth with epilepsy.

Introduction

The American Academy of Pediatrics (AAP) has been funded by the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) to serve as the National Coordinating Center for Epilepsy (Center) since 2013. The mission of the Center is to support professionals working to improve access to coordinated, comprehensive, and quality care for children and youth with epilepsy (CYE), particularly in medically underserved and/or rural areas, across the life-course. The goals of the Center are two-fold: 1) to provide national leadership through the building of partnerships, sharing of resources on best practices, and development of policies to improve access to coordinated and comprehensive care for CYE; and 2) to provide infrastructure and technical assistance to the Transforming Health Care for Children and Youth with Epilepsy program grantees.

For the current cooperative agreement through the *Innovations in Access to Care for Children and Youth with Epilepsy* project, the Center was tasked with conducting a national needs assessment. The needs assessment sought to determine the perception of existing gaps and challenges in health care for CYE, along with the assets, resources, capabilities, and strengths that patients, their families, and health care providers possess. The Center structured its needs assessment around the key priority areas of the following: access to care (including telehealth), quality of care (including shared decision-making, health care transition, and primary care provider knowledge of and confidence with epilepsy care), and systems/policies impacting care (including care coordination). Additional domains assessed included attitudes and feelings towards epilepsy and health equity considerations for children and youth with epilepsy.

Background

According to National Survey of Children's Health (NSCH) data, there are approximately 13.5 million children and youth with special health care needs (CYSHCN) in the United States (US).¹ Included among the CYSHCN are 470,000 children aged birth to 18 years living with epilepsy, the most common childhood neurologic condition in the US.² Epilepsy is a brain disorder where a person has recurring seizures.³ Seizures are sudden events that cause temporary changes in physical movement, sensation, behavior, or consciousness; they are caused by abnormal electrical and chemical changes in the brain.³

Epilepsy is a condition that requires complex, coordinated systems of primary and specialty care.⁴ A lack of awareness of the treatment options by providers can significantly affect a patient's quality of life.⁵ However, only roughly one-third of children with epilepsy have access to comprehensive health care.⁶ Nationally, the number of pediatric neurologists is at least 20% below the need, resulting in limited access to care for CYE, especially in rural and medically underserved areas/populations (MUA/Ps).^{4,7} Approximately 20% of Americans live in rural areas, while only 9% of the nation's physicians practice in these areas.⁴

Utilization of telehealth has been suggested as a potential solution to access to care barriers, particularly in providing care for those in rural areas and/or MUA/Ps as well as populations for whom traveling may be difficult, such as CYE.⁴ Despite the fact that research has shown improved patient outcomes and reduced care costs through the use of telehealth,⁸⁻¹⁰ patient-related barriers to widespread telehealth uptake, such as concerns about the quality of care delivered, security of health information, and loss of personal connection with the provider,¹¹ continue to persist.

Primary care providers (PCPs) are usually the first point of contact after a child has a seizure, which places them in an advantageous position to offer effective care; however, pediatricians and PCPs report not receiving adequate training in the recognition and treatment of seizures.^{4,7} Some pediatricians also report feeling uncomfortable with caring for children who have epilepsy.¹² Moreover, CYE are at an increased risk for developmental, intellectual, and mental health comorbidities, which underscores the need for high quality, coordinated systems of care.³

It is recommended that PCPs support families by engaging in a relationship with those for whom they care based on collaboration and shared decision-making (SDM) so that patients and parents/caregivers are more competent in the management of their own care over time.¹³ In a 2017 clinical report, the AAP provides a basis for a systematic approach to the implementation of SDM by PCPs for children with disabilities.¹⁴ SDM is particularly important during critical life events, for example when CYE transition from pediatric to adult health care.¹⁵ However, data from the 2016-2017 NSCH shows that 85.4% of

children aged 12-17 years did not receive the necessary services for transition to adult health care and 83% of CSHCN did not meet the national health care transition (HCT) measure which includes the domains of: 1) time alone with the doctor or health care clinician during last preventative visit; 2) the doctor or health care clinician worked with youth to gain self-management skills or understand changes in case at 18 years of age; and 3) the doctor or health care clinician talked with the youth about transitioning to doctors who treat adults.^{15,16} Perceived barriers to HCT among youth and families include a low desire to end a long-standing relationship with a pediatric provider.¹⁵ Providers report that a lack of communication and coordination between health professionals makes transition difficult, particularly for youth with medical complexities, such as CYE.¹⁵

The 2012 Institute of Medicine (IOM) report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, detailed disease prevalence, data collection, and measurement, as well as recommendations for improving quality of life for people with epilepsy through education, family engagement, community resources, and quality improvement.⁴ The report recommended that children and youth with epilepsy (CYE) and their families have access to the following: high quality health care; improved access to pediatric neurologists; a collaborative, patient/family-centered, team-based approach to care; a better informed primary care workforce; public education and awareness; and engagement of multiple stakeholders.⁴ Consistent with other literature, the report also noted absence of universal access to coordinated health care services that could provide the timely care needed to enhance quality of life for CYE.⁴

Methods

For this needs assessment, the Center utilized a mixed methods approach to collect and analyze data.

Survey Development

To develop the survey instruments used in the needs assessment, the Center conducted an examination of the peer-reviewed literature and adapted questions from the following sources: the [2019 National Survey of Children's Health](#); the [CAHPS® Health Plan Survey](#); and the AAP Access, Improvement, and Management of Epilepsy with Telehealth (AIM-ET) project surveys (Appendix A). Survey instruments were also intentionally identical to those used as part of the annual Transforming Health Care for Children and Youth with Epilepsy cross-site evaluation with grantees to allow for comparison of findings.

The parent/caregiver and young adult survey instruments included questions about demographic characteristics (age, state/territory, residential setting, child's race/ethnicity, insurance, and time since diagnosis); attitudes and feelings; access to care; telehealth; quality of care; shared decision-making; and health care transition. The AAP member survey instrument included questions about professional characteristics (training/background, primary vs specialty care, patient population, and ECHO participation); primary care provider knowledge, confidence, and communication (with specialist); specialist communication (with PCP); and telehealth. The parent/caregiver, young adult, and AAP member surveys can be found in Appendices B, C, and D, respectively.

Focus Group and Key Informant Interview Script Development

Focus group and key informant interview scripts were developed by Center staff in collaboration with members of the CYE Cabinet stakeholder group in a series of virtual meetings and email communications. The CYE Cabinet is a subset of the CYE Advisory Committee whose purpose is to help the Center operationalize its strategic objectives. Focus group and key informant interview scripts were divided into three main sections: 1) access to care (including telehealth); 2) quality of care (including shared decision-making and health care transition); and 3) systems/policies impacting care (including care coordination). All scripts can be found in Appendix E.

Participant Recruitment and Data Collection

The Center aimed to collect survey data from parents/caregivers of children and youth with epilepsy; young adults, aged 18 years or older, living with epilepsy; and members of the American Academy of Pediatrics, who comprise pediatricians and pediatric sub-specialists. The Center also sought to conduct focus groups with parents/caregivers of CYE, young adults, AAP members, and providers from the Transforming Health Care for Children and Youth with Epilepsy project. Finally, the Center aimed to conduct key informant interviews with members of its CYE Advisory Committee, a stakeholder group

comprised of health care providers, advocacy and community group leaders, and young adult representatives.

Needs assessment recruitment was done by leveraging the reach of the AAP, the Center, and relevant partners. Information about the needs assessment was sent out via multiple email communications, e-newsletters, listserv distribution lists, as well as through paid advertising on social media. Participants wishing to complete a survey needed to click on the survey link within the recruitment postings. They were then directed to an anonymous, electronic questionnaire on the SurveyMonkey platform. Survey data collection opened on March 26 and closed on June 30, 2021. Anyone wishing to participate in a focus group or key informant interview was directed to email the Center (epilepsy@aap.org) to indicate their interest in participating. Focus groups and key informant interviews were conducted by Center staff via Zoom between May 14 and June 15, 2021. The number of survey respondents and focus group/key informant interview participants can be seen in Table 1 below.

Table 1. Needs Assessment Participation by Target Population

	Survey Responses	FG/KII Participants
Parents/Caregivers of CYE	326	11
Young Adults	110	6
Health Care Providers*	31	9
CYE Advisory Committee Members	N/A	9

*For survey responses, “health care providers” include AAP members. For FG/KII participants, “health care providers” include AAP members and physicians/administrative staff affiliated with the *Transforming Health Care for Children and Youth with Epilepsy* project.

Quantitative Data Analysis

Statistical analysis was performed on all individual questions for the parent/caregiver, young adult, and AAP member surveys. Descriptive statistics were calculated to describe and summarize the data; analysis of variance (ANOVA) was used to determine whether differences exist among responses based on respondent demographic characteristics; and Spearman’s rank correlation (ρ) was used to evaluate the relationship between variables. The IBM SPSS 25 statistical software was used to analyze the quantitative data collected for the needs assessment. A p-value of 0.01 was used to determine statistical significance as there were multiple univariate analyses conducted.

Qualitative Data Analysis

Focus groups and key informant interviews were conducted virtually using the Zoom platform, and all sessions were audio recorded. Recordings were uploaded to transcription service Rev.com to create transcripts. Transcripts were then sent to an evaluation consultant for analysis. The transcript data were analyzed using qualitative methods, including content and thematic analysis.

Results

This section contains the most relevant and/or statistically significant results arising from the needs assessment. Full quantitative analysis can be found in Appendix F, and a summary of the qualitative analysis can be found in Appendix G.

Demographic and Professional Characteristics

Demographic Characteristics – Parents/Caregivers & Young Adults

Demographic characteristics for parents/caregivers of CYE and young adults who completed survey questionnaires can be found in Table 2 below. Demographic characteristics were not collected for focus group and key informant interview participants.

For parents/caregivers of CYE, the age of their children varied, with many being between five and nine years of age (26.7%) or between 10 and 14 years of age (22.7%). The majority of parent/caregiver respondents identified as being White, non-Hispanic (63.2%) and reported having private insurance (60.7%). A plurality reported living in a suburban setting (45.7%) and having their child's epilepsy diagnosis occur more than three years ago (37.7%).

Of the young adult respondents, the plurality was between 20 and 24 years of age (42.7%) and reported living in a suburban setting (48.2%). A majority of young adult respondents identified as White, non-Hispanic (72.7%), as having private insurance (55.5%), and as having their epilepsy diagnosed more than three years ago (75.5%).

Professional Characteristics – AAP Members

Demographic characteristics of AAP members were not captured in the survey instrument. However, professional characteristics of respondents can be seen in Table 3 below. In terms of professional training, the majority of respondents were medical doctors (71.0%). The respondents were nearly evenly split between primary care (51.6%) and neurology (48.4%). Most respondents reported providing care exclusively to pediatric patients (74.2%), and most respondents had not previously participated in an Extension for Community Healthcare Outcomes (ECHO) program (80.7%).

Table 2. Demographic Characteristics of Respondents, Parents/Caregivers & Young Adults

	Parents/Caregivers, % (n)	Young Adults, % (n)
	N = 326	N = 110
Age (of Child)		
0-4 yrs	13.2% (43)	0.0% (0)
5-9 yrs	26.7% (87)	0.0% (0)
10-14 yrs	22.7% (74)	0.0% (0)
15-19 yrs	15% (49)	15.5% (17)
20-24 yrs	9.2% (30)	42.7% (47)
25-29 yrs	3.1% (10)	37.3% (41)
30-34 yrs	0.0% (0)	4.5% (5)
Skipped Question	10.1% (33)	0.0% (0)
Race/Ethnicity		
African American/Black	9.8% (32)	3.6% (4)
American Indian/Alaska Native	5.8% (19)	2.7% (3)
Asian/Native Hawaiian/Pacific Islander	2.1% (7)	4.5% (5)
Hispanic/Latino	6.4% (21)	12.7% (14)
White, non-Hispanic	63.2% (206)	72.7% (80)
Other/Declined to Identify	3.0% (10)	3.6% (4)
Skipped Question	9.5% (31)	0.0% (0)
Residential Setting		
Urban	30.7% (100)	24.6% (27)
Suburban	45.7% (149)	48.2% (53)
Rural	14.1% (46)	27.3% (30)
Skipped Question	9.5% (31)	0.0% (0)
Insurance		
Private	38.0% (124)	55.5% (61)
Public	26.7% (87)	23.6% (26)
Both	22.7% (74)	10.9% (12)
None	2.5% (8)	6.4% (7)
Don't Know	0.31% (1)	3.6% (4)
Skipped Question	9.8% (32)	0.0% (0)
Time Since (Child's) Epilepsy Diagnosis		
0-6 mos	10.1% (33)	3.6% (4)
7 mos-1 yr	23.0% (75)	8.2% (9)
> 1 yr, < 3 yrs	19.3% (63)	12.7% (14)
> 3 yrs	37.7% (123)	75.5% (83)
Skipped Question	9.8% (32)	0.0% (0)

Table 3. Professional Characteristics of Respondents, AAP Members

	AAP Members, % (n)
	N = 31
Professional Training	
<i>Doctor of Osteopathy (DO)</i>	3.2% (1)
<i>Medical Doctor (MD)</i>	71.0% (22)
<i>Nurse Practitioner</i>	3.2% (1)
<i>Physician Assistant</i>	0.0% (0)
<i>Registered Nurse</i>	6.5% (2)
<i>Social Worker</i>	9.7% (3)
<i>Other</i>	6.5% (2)
Type of Practice	
<i>Primary Care</i>	51.6% (16)
<i>Neurology</i>	48.4% (15)
Patient Population	
<i>Children, Youth, and Adults</i>	22.6% (7)
<i>Children and Youth</i>	74.2% (23)
<i>Adults</i>	3.2% (1)
ECHO Participation	
<i>Yes</i>	16.1% (5)
<i>No</i>	80.7% (25)
<i>Don't Know</i>	3.2% (1)

Epilepsy Attitudes and Feelings

Attitudes and Feelings – Quantitative Findings

On the parent/caregiver survey questionnaire, respondents were asked to indicate their attitudes and feelings toward their child's epilepsy. The parent/caregiver attitudes and feelings domain included five items, which were measured on a 5-point Likert scale to determine level of agreement with each statement (1=disagree entirely, 5=agree entirely). Mean scores for each of the items assessed (eg, people who know my child has epilepsy treat them differently) were then summed to create an aggregate score for the attitudes and feelings domain (range=0-25). Aggregate mean scores for attitudes and feelings were subsequently stratified by demographic characteristics to determine the presence of statistically significant differences.

When considering mean scores for individual items (Table 4), parents/caregivers most strongly agreed with epilepsy attaching a stigma to their child ($M=3.89$, $SD=1.05$). When looking at the overall domain, time since child's epilepsy diagnosis had a statistically significant impact on attitudes and feelings. Parents/caregivers whose children received their epilepsy diagnosis either between 0-6 months ($M=17.21$, $SD=4.33$, $p<0.001$) or between 7 months and 1 year ($M=18.99$, $SD=3.72$, $p<0.001$) prior to completing the survey reported highest aggregate mean scores for the attitudes and feelings domain, indicating higher

levels of negative feelings about their child’s epilepsy than parents/caregivers of children who received their diagnosis more than a year prior to survey completion. Spearman rank correlations (ρ) were also assessed for parent/caregiver attitudes toward their child’s epilepsy. Parents/caregivers who reported positive perceptions of shared decision-making also reported feeling less negative about their child’s epilepsy ($\rho=-0.246, p<0.001$).

Table 4. Epilepsy Attitudes & Feelings, Parents/Caregivers of CYE*

	Mean	SD
People who know my child has epilepsy treat them differently	3.59	1.16
It really doesn’t matter what I say to people about my child’s epilepsy, they usually have their minds made up	3.36	1.23
My child always has to prove themselves because of their epilepsy	3.27	1.29
Because of the epilepsy, my child will have trouble finding a partner or spouse	3.37	1.31
In many people’s minds, epilepsy attaches a stigma or label to my child	3.89	1.05

*Respondents were asked to “please rate the following statements regarding attitudes and feelings about epilepsy” on a 5-point Likert scale: 1=Disagree Entirely; 2=Disagree Somewhat; 3=Neither Agree nor Disagree; 4=Agree Somewhat; 5=Agree Entirely.

Young adults were also asked to indicate their attitudes and feelings toward their epilepsy. The young adult attitudes and feelings domain included 8 items, which were measured on a 5-point Likert scale to determine the frequency with which respondents experienced each attitude/feeling (1=never, 5=very often). Mean scores for each of the items assessed (eg, how often you feel embarrassed about your epilepsy) were then summed to create an aggregate score for the attitudes and feelings domain (range=0-40). Aggregate mean scores for attitudes and feelings were subsequently stratified by demographic characteristics to determine the presence of statistically significant differences.

As indicated in Table 5 below, the feeling/attitude experienced most frequently by young adult respondents was feeling different from others because of their epilepsy ($M=3.73, SD=1.00$). Among young adult respondents, demographic characteristics did not have a statistically significant impact on attitudes and feelings. Spearman rank correlations (ρ) were also assessed for young adult attitudes toward their epilepsy. Young adults who reported positive perceptions of shared decision-making also reported feeling less negatively about their epilepsy ($\rho=-0.276, p<0.001$).

Table 5. Epilepsy Attitudes & Feelings, Young Adults*

	Mean	SD
How often do you feel different from others because you have epilepsy?	3.73	1.00
How often do you feel others may not like you if they know you have epilepsy?	2.96	1.38
How often do you feel others are uncomfortable with you because of your epilepsy?	3.23	1.27
How often do you feel others may not want to be friends with you if they know you have epilepsy?	2.55	1.30
How often do you feel others would not want to go out with you or ask you to events if they know you have epilepsy?	3.09	1.42
How often do you feel embarrassed about your epilepsy?	3.14	1.23
How often do you keep your epilepsy a secret from others?	2.94	1.38
How often do you avoid talking to others about your epilepsy?	2.94	1.46

*Respondents were asked to “please rate the following statements regarding attitudes and feelings about epilepsy” on a 5-point Likert scale: 1=Never; 2=Not Often; 3=Sometimes; 4=Often; 5=Very Often.

Access to Care

Access to Care – Quantitative Findings

Parent/caregiver and young adult survey questionnaires assessed respondents’ perceptions of access to care. The parent/caregiver and young adult access to care domain included four items, which were measured on a 4-point Likert scale to determine the frequency with which respondents believed each access to care item occurred in the past year (1=never, 4=always). Mean scores for each of the items assessed (eg, schedule an appointment with a specialist as soon as needed) were then summed to create an aggregate score for the access to care domain (range=0-16). Aggregate mean scores for access to care were subsequently stratified by demographic characteristics to determine the presence of statistically significant differences.

When considering individual items (Table 6 below), mean scores for both parents/caregivers and young adults indicate that both groups believe they can “usually” access care across all four items assessed.

When looking at the overall domain of access to care for parents/caregivers of CYE, perceptions of access to care were impacted by the age of the child and the time since child’s epilepsy diagnosis.

Parents/caregivers of CYE between the ages of 0 and 4 years ($M=11.48$, $SD=3.23$, $p=0.006$) and those of CYE between the ages of 5 and 9 years ($M=11.92$, $SD=2.58$, $p=0.006$) reported lower aggregate mean scores for perceptions of access to care than parents/caregivers of CYE in any other age group. Parents/caregivers whose children received their epilepsy diagnosis between 7 months and 1 year prior to completing the survey reported lowest aggregate mean scores for the access to care domain ($M=10.97$, $SD=2.65$, $p<0.001$). For young adult respondents, demographic characteristics did not have a statistically significant impact on perceptions of access to care.

Spearman rank correlations (ρ) were also assessed for parent/caregiver and young adult perceptions of access to care. Both parents/caregivers ($\rho=0.719, p<0.001$) and young adults ($\rho=0.658, p<0.001$) who reported positive perceptions of shared decision-making also reported more positive perceptions of access to care. Additionally, young adult respondents who reported better perceptions of access to care also reported more positive perceptions of quality of care ($\rho=0.601, p<0.001$).

Table 6. Perceived Access to Care, Parents/Caregivers & Young Adults*

	Parents/Caregivers		Young Adults	
	Mean	SD	Mean	SD
Make it easy to get necessary care, tests, or treatment	3.25	0.81	3.04	0.99
Schedule an appointment with a specialist as soon as needed	2.98	1.00	3.07	1.03
Schedule an appointment for illness/injury as soon as needed	3.23	0.83	3.14	0.91
Schedule a non-urgent appointment as soon as needed	3.13	0.90	3.13	0.94

* Based on the primary care provider visits in the past year, respondents were asked to indicate how often their medical care team did the following, based on a 4-point Likert scale: 1=Never; 2=Sometimes; 3=Usually; =Always.

Access to Care – Qualitative Findings

Key themes from parent/caregiver focus groups centered on barriers to access to care. The main access to care barriers experienced by parents/caregivers of CYE included lack of access to specialty care (difficulty finding a provider; waiting months for an appointment; and having “to fight” to get an appointment), not being taken seriously by primary care and specialty care providers (being treated with a “dismissive” attitude; delays in seeing a specialist due to not being taken seriously by pediatrician; and demonstrated “lack of urgency”), and difficulty accessing the provider directly (no response when trying to contact provider; and seeing the nurse practitioner instead of the pediatric neurologist).

Key access to care themes that emerged from young adult focus groups included feeling like the “doctor did not respect me;” lack of trust/connection with doctor; and having to change doctors multiple times before finding one whom the young adult felt understood/respected them.

Access to care barriers noted by health care providers and stakeholders included geographic/transportation-related barriers for patients and families (traveling long distances; lacking reliable transportation; and difficulty traveling for CYE dependent on supportive technology), capacity-related barriers (lack of sufficient epilepsy monitoring units and Level 4 epilepsy centers; lack of agreed-upon treatment and referral algorithms; and lack of sufficient pediatric epileptologists to meet demand), and patient-related barriers (difficulty for patients to hear diagnosis, which they associate with stigma; varying levels of health and digital literacy; and lack of urgency and/or adherence on the part of the patient and parent/caregiver).

Telehealth

Telehealth – Quantitative Findings

Parent/caregiver and young adult survey questionnaires assessed respondents' perceptions of telehealth. The parent/caregiver and young adult perceptions of telehealth domain included seven items, which were measured on a 5-point Likert scale to determine level of agreement with each statement (1=disagree entirely, 5=agree entirely). Mean scores for each of the items assessed (eg, telehealth made it easier for me to see the clinician) were then summed to create an aggregate score for the telehealth domain (range=0-35). Aggregate mean scores for telehealth were subsequently stratified by demographic characteristics to determine the presence of statistically significant differences.

When considering individual items (Table 7), parents/caregivers of CYE most strongly agreed with being able to easily talk to the clinician using the telehealth system ($M=4.12$, $SD=0.99$), while young adults most strongly agreed that telehealth was an acceptable way to get health care services ($M=3.95$, $SD=0.96$). The item eliciting the least amount of agreement for both parents/caregivers ($M=3.39$, $SD=1.22$) and young adults ($M=2.88$, $SD=1.46$) was preferring to see a clinician via telehealth rather than in-person. There were no statistically significant differences regarding perceptions of telehealth based on demographic characteristics of respondents, either for parents/caregivers or for young adults.

Table 7. Perceptions of Telehealth, Parents/Caregivers & Young Adults

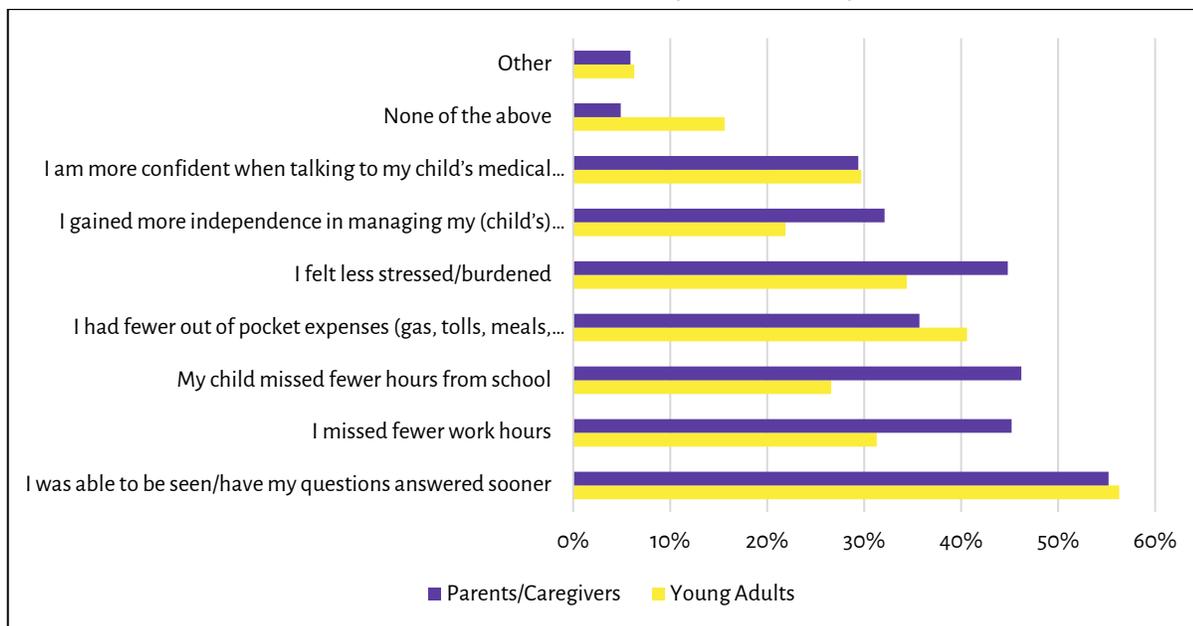
	Parents/Caregivers		Young Adults	
	Mean	SD	Mean	SD
Telehealth is an acceptable way to get health care services	3.83	1.05	3.95	0.96
I could easily talk to clinicians using the telehealth system	4.12	0.99	3.86	1.06
I could see the clinician as well as if we met in person	3.89	1.12	3.67	1.24
Telehealth made it easier for me to see the clinician	3.96	1.10	3.89	1.13
I think the visits provided over the telehealth system were as good as in-person visits	3.69	1.16	3.18	1.26
I would rather see a clinician through telehealth than travel to see them in person	3.39	1.22	2.88	1.46
I would recommend telehealth to another person	3.98	1.07	3.92	1.07

*Respondents were asked to rate the following statements regarding use of telehealth strategies based on a 5-point Likert scale: 1=Disagree Entirely; 2=Disagree Somewhat; 3=Neither Agree nor Disagree; 4=Agree Somewhat; 5=Agree Entirely.

Spearman rank correlations (ρ) were also assessed for parent/caregiver and young adult perceptions of telehealth. Parents/caregivers reporting more positive perceptions of telehealth also reported better quality of care ($\rho=0.380$, $p<0.001$), and young adults who reported positive perceptions of telehealth also reported more positive perceptions of shared decision-making ($\rho=0.276$, $p=0.023$).

Regarding benefits of telehealth, as can be seen in Chart 1 below, more than half of both parent/caregiver (55.20%) and young adult respondents (56.30%) cited being seen/having their questions answered sooner as a major benefit. Other key telehealth benefits for parents/caregivers include having their child miss fewer school hours (46.2%), missing fewer work hours (45.2%), and feeling less stressed/burdened (44.8%). For young adults, other benefits of telehealth include fewer out of pocket expenses (40.6%), feeling less stressed/burdened (34.4%), and missing fewer work hours (31.3%).

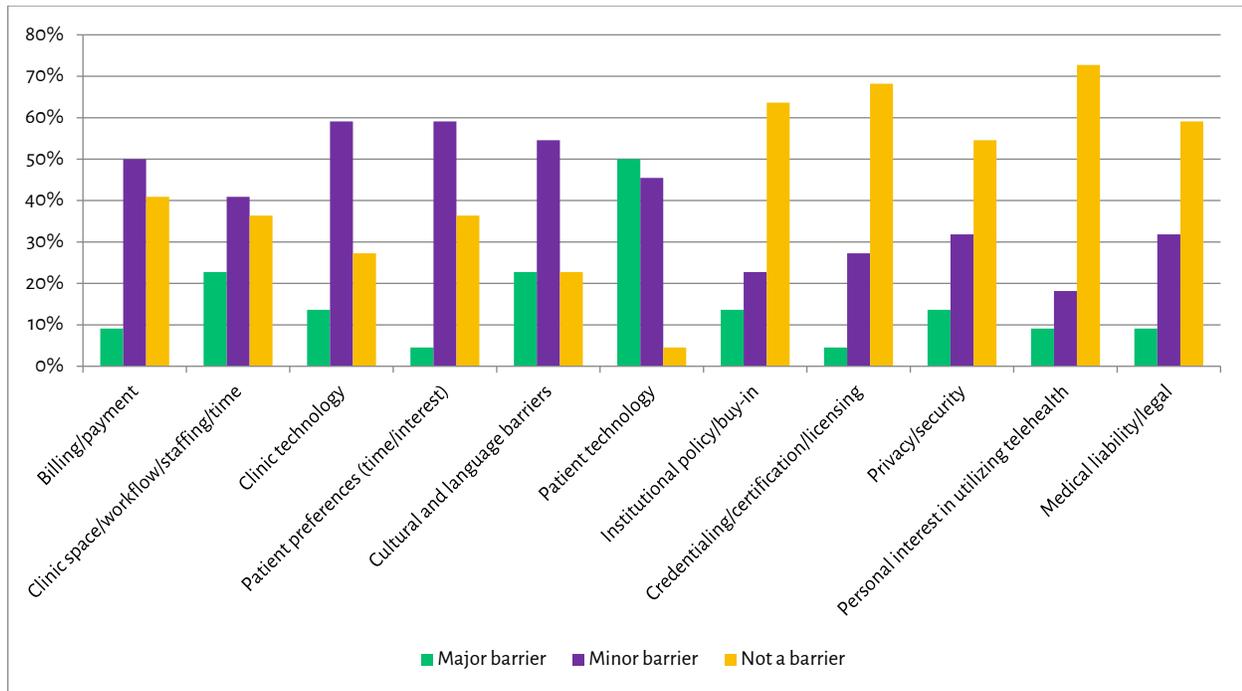
Chart 1. Perceived Benefits of Telehealth, Parents/Caregivers & Young Adults



Of parent/caregiver respondents who indicated having a telehealth visit in the last year, 41.6% prefer telehealth visits, 42.5% prefer in-person visits, and 16.0% have no preference. Of young adult respondents who indicated having a telehealth visit in the last year, only 24.6% prefer telehealth visits, while 64.6% prefer in-person visits and 10.8% have no preference.

For perceived barriers to telehealth, AAP members were asked to assess eleven items as a major barrier, a minor barrier, or not a barrier. Half of the AAP member respondents (50.0%) cited patient technology as a major barrier to telehealth. Perceived minor barriers included clinic technology (59.1%), patient preferences (59.1%), and cultural and language barriers (54.6%). Personal interest in utilizing telehealth (72.7%), credentialing/certification/licensing (68.2%), and institutional policy/buy-in (63.6%) were most frequently cited as not being barriers to telehealth (Chart 2 below).

Chart 2. Perceived Barriers to Telehealth, AAP Members



Telehealth – Qualitative Findings

Overall parent/caregiver experiences with telehealth were positive, comfortable, and convenient. Parents/caregivers reported that telehealth eliminates the stress related to taking the child out of their regular routine and subjecting them to additional stimulation. Telehealth eliminates the need to maneuver with wheelchairs or other supportive technology, and it allows the child to stay comfortable at home. Parents/caregivers also expressed that they may not have liked telehealth when their child was first diagnosed with epilepsy or when their condition was less stable. However, now that their child’s epilepsy is stabilized, they like telehealth for routine appointments.

While young adults described generally having positive experiences with telehealth; they also noted several limitations to telehealth utilization. Telehealth technical difficulties can be an issue; telehealth is challenging for providers and patients who do not have much experience using telehealth platforms. Most young adults reported that they prefer in-person appointments, but they acknowledged that telehealth is easier and more efficient.

In their focus groups and key informant interviews, health care providers and stakeholders acknowledged both the advantages and limitations of telehealth. Benefits of telehealth include eliminating the need for patients to travel, which is especially helpful for those who are not near a Level 4 epilepsy center or have other travel-related challenges. Telehealth also allows parents/caregivers to capture and send videos of seizures that occur when the patient is not in an epilepsy monitoring unit. Furthermore, telehealth is

helpful in enabling providers to see patients in their home environment, which may provide information not typically available to the providers. Limitations of telehealth include lack of patient technology and/or reliable internet access needed for a successful visit; patients and parents/caregivers being distracted at the time of appointment; and parents/caregivers attending a telehealth appointment without the child/patient present.

Quality of Care

Quality of Care – Quantitative Findings

To understand overall perceptions of quality of care, parents/caregivers and young adults were asked to assess four items within the quality of care domain on a scale of 0-10, with 0 being the worst and 10 being the best. As can be seen in Table 8 below, parents/caregivers rated each item more favorably than young adults, and satisfaction with the seizure action plan was lowest among both groups of respondents.

Table 8. Perceived Quality of Care, Parents/Caregivers & Young Adults

	Parents/Caregivers		Young Adults	
	Mean	SD	Mean	SD
Overall Health Care	8.07	2.06	7.55	2.07
Primary Care	8.07	1.96	7.54	2.07
Specialty Care	8.02	2.15	7.78	2.53
Seizure Action Plan	7.61	2.37	6.71	3.10

* Based on “the visits to your child’s primary care provider in the past year, please rate your medical care team for each of the following categories. Ratings are on a scale of 0-10, with 0 being the worst and 10 being the best.”

Mean scores for each of the items assessed (eg, overall health care) were then summed to create an aggregate score for the quality of care domain (range=0-40). Aggregate mean scores for quality of care were subsequently stratified by demographic characteristics to determine the presence of statistically significant differences. For parents/caregivers of CYE, age of the child, race/ethnicity, and insurance type did not impact respondents’ perceptions of quality of care. However, perceptions of quality of care were impacted by residential setting and time since the child’s epilepsy diagnosis. Parents/caregivers of CYE living in rural settings reported statistically significantly lower aggregate mean scores for the quality of care domain ($M=28.49$, $SD=9.18$, $p<0.001$) than those living in urban or suburban settings. Additionally, parents/caregivers whose children received their epilepsy diagnosis between 0 and 6 months prior to completing the survey reported statistically significantly lower aggregate mean scores for the quality of care domain ($M=25.53$, $SD=7.11$, $p<0.001$) as compared to those whose children received their epilepsy diagnosis 7 months or more prior to completing the survey. For young adult respondents, demographic characteristics did not have a statistically significant impact on perceptions of quality of care.

Spearman rank correlations (ρ) were also assessed for parent/caregiver and young adult perceptions of quality of care. Both parents/caregivers ($\rho=0.434, p<0.001$) and young adults ($\rho=0.513, p<0.001$) who reported positive perceptions of shared decision-making also reported more positive perceptions of quality of care. Additionally, young adult respondents who reported better perceptions of access to care also reported more positive perceptions of quality of care ($\rho=0.601, p<0.001$).

Quality of care for children and youth with epilepsy was also assessed via the AAP member survey through questions on two domains: 1) primary care provider knowledge of caring for CYE and 2) primary care provider confidence in caring for CYE. The PCP knowledge domain comprised 8 items, which were measured on a 4-point Likert scale to determine knowledge of each item (1=not knowledgeable at all, 4=very knowledgeable). The PCP confidence domain included 11 items, which were measured on a 4-point Likert scale to determine confidence with each item (1=not at all confident, 4=very confident). PCPs were most knowledgeable when it came to knowing when to refer to a specialist ($M=3.30, SD=0.71$) and least knowledgeable when it came to creating a health care transition office policy ($M=2.30, SD=0.67$). Similarly, PCPs were most confident about knowing when to refer patients with epilepsy to a specialist ($M=3.22, SD=1.09$). They were least confident about managing side effects of medications for CYE ($M=1.78, SD=0.67$). Additional information can be seen in Tables 9 and 10 below.

Table 9. Primary Care Provider Knowledge of Caring for CYE Patients

	Mean	SD
Understanding medication management for seizures	2.50	0.53
Treating behavioral health comorbidities in CYE	2.50	0.53
Educational, emotional, and social issues faced by CYE	2.70	0.48
Safety concerns (such as driving laws in your state) for CYE	2.50	0.53
Understanding diagnostic tests associated with epilepsy	2.70	0.67
Creating a health care transition office policy	2.30	0.67
Knowing when to refer to a specialist	3.30	0.71
Understanding the risks of epilepsy, including SUDEP	2.40	0.52

*Respondents were asked to indicate the extent to which they felt knowledgeable about the following aspects for CYE care based on a 4-point Likert scale: 1=Not at all Knowledgeable; 2=Not very Knowledgeable; 3=Knowledgeable; 4=Very Knowledgeable.

Table 10. Primary Care Provider Confidence with Caring for CYE Patients

	Mean	SD
Providing primary care for CYE	3.10	0.57
Managing side effects of medications for CYE	1.78	0.67
Encouraging CYE to adhere to their plan of care	2.50	0.97
Assessing comorbidities in CYE	2.30	0.82
Managing comorbidities in CYE	2.40	0.70
Understanding diagnostic tests associated with epilepsy	2.30	1.06
Discussing age-appropriate transition issues	2.10	0.74
Discussing impact of seizures on everyday life	2.00	0.67
Educating other clinical staff about seizures	2.00	0.67
Knowing when to refer patients with epilepsy to a specialist	3.22	1.09
Discussing the risks of epilepsy, including SUDEP	2.10	0.88

*Respondents were asked to indicate the extent to which they felt confident in the following aspects of CYE care based on a 4-point Likert scale: 1=Not at all confident; 2=Not very confident; 3=Confident; 4=Very confident.

Quality of Care – Qualitative Findings

The most significant quality of care issue raised by both parents/caregivers and young adults was not being respected and not being taken seriously by the provider. Parents/caregivers cited being treated in a “dismissive” manner and feeling “abandoned” by their provider. They also discussed the fact that they did not receive any general education/resources, information about medications, or referrals from their provider. Young adults also cited a lack of respect/being taken seriously by their provider, poor communications skills on the part of the provider, and not being directed to reputable sources of information. Young adults also expressed dismay over providers’ lack of willingness to discuss sudden, unexpected death in epilepsy (SUDEP) with them. Young adults would rather have the difficult discussion about SUDEP with a medical professional than stumble upon it when looking for information/resources on the internet at home.

Health care providers and stakeholders focused their quality of care responses on improving primary care provider ability to diagnose and treat epilepsy. Key themes focused on additional training and continuing education on epilepsy and seizure management, the development of algorithms and decision support tools to help primary care providers with diagnosis, treatment, and referral, and more education about epilepsy co-morbidities, particularly those around mental and behavior health. There was also feedback about the need to shift the culture by having primary care providers take on more responsibility in caring for CYE as opposed to immediately referring to a neurologist/epileptologist, especially when access to a specialist is limited.

Shared Decision-making

Shared Decision-making – Quantitative Findings

Parent/caregiver and young adult survey questionnaires assessed respondents' perceptions of shared decision-making. The shared decision-making domain included five items, which were measured on a 4-point Likert scale to determine how often parents/caregivers and young adults perceive an SDM indicator occurring in a health care visit (1=never, 5=always). Mean scores for each of the items assessed (eg, spent enough time with you) were then summed to create an aggregate score for the SDM domain (range=0-20). Aggregate mean scores for SDM were subsequently stratified by demographic characteristics to determine the presence of statistically significant differences.

As indicated in Table 11 below, both parents/caregivers and young adults reported that their health care team “usually” did all items associated with the SDM domain. Young adult scores were slightly lower than parent/caregiver scores for SDM for each individual item assessed. When looking at the overall domain of SDM for parents/caregivers of CYE, perceptions of SDM were impacted by age of the child, insurance type, and time since the child’s epilepsy diagnosis. Parents/caregivers of CYE between the ages of 0 and 4 years reported lower aggregate mean scores ($M=14.74$, $SD=4.24$, $p<0.001$) for perceptions of SDM than parents/caregivers of CYE in any other age group. Additionally, parents/caregivers of CYE with both private and public insurance reported statistically significantly higher aggregate mean scores ($M=17.16$, $SD=3.27$, $p=0.009$) for the SDM domain than those with only private insurance, only public insurance, no insurance, or those not knowing their insurance status. Finally, parents/caregivers whose children received their epilepsy diagnosis between 0 and 6 months prior to completing the survey ($M=15.23$, $SD=3.17$, $p<0.001$) and those whose children received their epilepsy diagnosis between 7 months and 1 year prior to completing the survey ($M=14.28$, $SD=3.59$, $p<0.001$) reported statistically significantly lower aggregate mean scores for the SDM domain as compared to respondents whose children received their epilepsy diagnosis 1 year or more prior to completing the survey. For young adult respondents, demographic characteristics did not have a statistically significant impact on perceptions of shared decision-making.

Table 11. Perceived Shared Decision-making, Parents/Caregivers & Young Adults

	Parents/Caregivers		Young Adults	
	Mean	SD	Mean	SD
Spent enough time with you	3.28	0.83	2.95	0.99
Listened carefully to you	3.31	0.81	3.20	0.92
Explaining things in a way you could understand	3.29	0.82	3.22	0.85
Involved you in decisions about care and treatments	3.37	0.85	3.20	0.93
Made you feel like a partner in health care	3.34	0.83	3.13	0.96

*Based on the visits to their primary care provider in the past year, respondents were asked to indicate how often their medical care team did the following based on a 4-point Likert scale: 1=Never; 2=Sometimes; 3=Usually; 4=Always.

Spearman correlations (ρ) were also assessed for parent/caregiver and young adult perceptions of shared decision-making. As stated above, for parents/caregivers, SDM was positively correlated with perceptions of access to care ($\rho=0.719, p<0.001$) and perceptions of quality of care ($\rho=0.434, p<0.001$).

Parents/caregivers who reported positive perceptions of SDM also reported feeling less negative about their child's epilepsy ($\rho=-0.246, p<0.001$). For young adults, SDM was positively correlated with perceptions of access to care ($\rho=0.658, p<0.001$), perceptions of quality of care ($\rho=0.513, p<0.001$), and perceptions of telehealth ($\rho=0.276, p=0.023$). Young adults who reported positive perceptions of SDM also reported feeling less negative about their epilepsy ($\rho=-0.276, p<0.001$).

Shared Decision-making – Qualitative Findings

To improve shared decision-making, parents/caregivers had the following suggestions: providers should complete additional training to improve their communication skills; providers need to give parents/caregivers all relevant information on their child's epilepsy, including SUDEP; and providers need to meet the parents/caregivers "where they are" (provide information in layman's terms, do not overwhelm the parents/caregivers).

Young adults had suggestions for improving shared decision-making. Young adults want more information about treatment options, including medications and their side effects. Young adults are also interested in receiving more information about SUDEP in their appointments. Young adults also stated the need for the provider to use easy-to-understand, age-appropriate language when talking to patients and the need for the provider to direct patients to reputable internet resources. Finally, young adults emphasized the desire to have their epilepsy treated in a more holistic manner.

Health Care Transition

Health Care Transition – Quantitative Findings

Parent/caregiver and young adult surveys included three questions regarding health care transition (HCT), and results can be seen in Table 12 below. Of the parents/caregivers whose children were at least 12 years old (N=162), less than half (47.5%) reported having their child speak with a member of their health care team privately. However, 64.4% of parent/caregiver respondents reported their health care team teaching their child self-management skills and 66.5% reported their health care team explaining the difference between pediatric and adult care. For young adult respondents, 59.0% reported speaking with a member of their health care team privately/without a parent/caregiver present, 77.9% reported their health care team teaching them self-management skills, while only 41.1% reported their health care team explaining the difference between pediatric and adult care to them.

Table 12. Health Care Transition, Parents/Caregivers & Young Adults

	Parents/Caregivers			Young Adults		
	Yes	No	Don't Know	Yes	No	Don't Know
(Child) Spoke with health care team privately	47.5%	51.9%	0.6%	59.0%	41.0%	0.0%
Health care team teaches self-management skills	64.4%	34.4%	1.3%	77.9%	20.0%	2.1%
Health care team explains difference between pediatric and adult care	66.5%	30.4%	3.1%	41.1%	48.4%	10.5%

Health Care Transition – Qualitative Findings

Most parents/caregivers who participated in focus groups reported that their child is not ready for transition yet. Many expressed that they are not ready to think about it and that it feels too overwhelming. Parents/caregivers are hoping that their child's current providers will steer them in the right direction for adult care when the time comes.

Young adults participating in the needs assessment reported mixed experiences with health care transition. Some participants did not go through the transition process because they were diagnosed as adults. Others, who were diagnosed as children and went through the transition process, reported that it would have been helpful to have more information about the adult physicians. They would have liked to know the difference between pediatric and adult care and how to prepare for seeing an adult provider.

Communication and Care Coordination

Communication and Care Coordination – Quantitative Findings

The AAP member survey included communication-related questions for both primary care providers and specialists. The communication domain included four items which were measured on a 4-point Likert scale (1=none of my patients, 4=all of my patients). As can be seen in Table 13 below, PCPs rated being able to reach the neurologist/epileptologist when needed highest ($M=3.10, SD=0.74$) and care coordination between primary and epilepsy care lowest ($M=2.50, SD=0.85$). Table 14 below shows that specialists rated being available to PCPs for questions about shared patients highest ($M=4.00, SD=0.00$) and care coordination between primary and epilepsy care lowest ($M=2.60, SD=0.83$).

Table 13. Primary Care Provider Perception of Communication and Care Coordination

	Primary Care	
	Mean	SD
I am adequately informed of the currently epilepsy management plan	2.80	0.63
I am informed in a timely manner about changes in the management plan	2.80	0.63
I am able to reach the neurologist/epileptologist when needed	3.10	0.74
I believe epilepsy care and primary care are well coordinated	2.50	0.85

*Primary care providers were asked to evaluate the following aspects of their communication with specialty care providers (neurologists/epileptologists) based on a 4-point Likert scale: 1=None of my patients with epilepsy; 2= Some of my patients with epilepsy; 3=Most of my patients with epilepsy; 4=All of my patients with epilepsy.

Table 14. Specialty Care Provider Perception of Communication and Care Coordination

	Primary Care	
	Mean	SD
I keep the PCPs who care for my epilepsy patients adequately informed of the current management plan	3.00	0.93
I inform the PCPs who care for my epilepsy patients in a timely manner about changes to the management plan	2.87	0.92
I am able available when a PCP needs to reach me about a patient with epilepsy for whom we both care	4.00	0.00
I believe epilepsy care and primary care are well coordinated	2.60	0.83

*Specialty care providers were asked to evaluate the following aspects of their communication with primary care providers based on a 4-point Likert scale: 1=None of my patients with epilepsy; 2=Some of my patients with epilepsy; 3=Most of my patients with epilepsy; 4=All of my patients with epilepsy.

Communication and Care Coordination – Qualitative Findings

Parents/caregivers of children and youth with epilepsy reported a lack of communication and sharing of information between primary care and specialty care providers. Parents/caregivers identified themselves as the care coordinator, not someone from the practice or health care team. They also reported feeling like time is being wasted during appointments because they are repeating information that is already in the medical records but is not being read in advance of the visit.

Health care providers and stakeholders pointed to more systemic issues with care coordination. A frequently cited barrier to streamlined and successful care coordination was that primary care and specialty care providers use different electronic health record (EHR) systems. Lack of time to engage in meaningful care coordination and limited compensation for time spent communicating with each other were also cited as care coordinating pain points. Identifying and documenting primary vs. specialty care roles and responsibilities around data sharing and patient follow-up was provided as a suggestion to improve care coordination.

Health Equity Considerations for Children and Youth with Epilepsy

Equity-related questions were included as part of the focus groups and key informant interviews conducted with health care providers and other stakeholders.

Respondents noted the importance of considering cultural factors when thinking through equitable care for children and youth with epilepsy. Some health care providers reported that cultural factors may impact a patient's comfort level with asking questions and being part of the decision-making process. They recommended providing health literacy education in a way that is respectful of these types of cultural perspectives to improve outcomes. Additionally, it was suggested that, if possible, patients should be matched with providers who speak the same language because using an interpreter can result in less time during the appointment to interact directly with the patient and family.

Regarding telehealth, focus group and key informant interview participants cited a lack of equitable access. They also noted that for some patients, telehealth was the only option due to geographic location and travel barriers. There was also a perceived lack of standards around when and when not to use telehealth in place of in-person visits.

It was stated that insurance has a significant impact on access to and quality of care for CYE patients. Participants reported that those on private insurance may have higher deductibles and out-of-pocket costs, while those on public insurance may have a harder time accessing more specialized care, such as neuropsychological testing. One participant was quoted as saying “insurance dictates a lot of your access.”

Among focus group and key informant interview participants, additional considerations for health equity for children and youth with epilepsy included increased emergency department visits for CYE with complex comorbidities, quality of life and mental health inequities, and long-standing issues with and mistrust of the health care system.

Discussion

Based on the findings of the needs assessment as presented above, there are several important gaps, challenges, and opportunities related to access to care, quality of care, and systems/policies impacting care for CYE.

Access to Care

Regarding access to care, reported barriers centered on lack of access to neurologists/epileptologists and Level 4 epilepsy centers and transportation challenges. Inequities faced by CYE and their parents/caregivers related to demographics, socioeconomic status, neurological complexity, and ability to self-advocate were also acknowledged. While survey respondents and focus group/key informant interview participants generally agreed that telehealth is beneficial for CYE and their families, there was still a patient preference for in-person visits. Ongoing challenges with telehealth include lack of access to reliable internet, equipment that can support telehealth appointments, and knowledge about how to use telehealth platforms. While telehealth can solve the access to care issue for some CYE patients, it can also exacerbate existing inequities, particularly for those who do not have access to broadband/internet or those who may not have access to a private space.

Quality of Care

When considering quality of care, parents/caregivers and young adults emphasized the importance of having a good relationship with their providers and placed a great deal of value on feeling supported and respected. Perceptions of shared decision-making impacted almost all other areas of care, including perceptions of access, perceptions of quality, perceptions of telehealth, and even the attitudes and feelings of parents/caregivers and young adults toward epilepsy. Parents/caregivers and young adults expressed the need to be provided with more information upon diagnosis; additional information about treatment options, medications, and side effects; and more direction toward reputable online resources. There was a consensus among parent/caregiver and young adult participants about the need for health care providers to improve their communication, especially when discussing difficult subjects such as SUDEP. Parents/caregivers and young adults would prefer to hear about SUDEP from a professional during a medical appointment rather than coming across it on the internet, potentially from a less than reputable source.

Knowledge of and confidence with providing care to CYE patients among primary care providers remains low, with PCPs feeling most comfortable with providing general pediatric care and/or referring CYE patients to neurologists/epileptologists. Furthermore, participants consistently expressed the need for

more PCP education, particularly on seizure safety, seizure action plans, and understanding anti-seizure medications.

Systems and Policies

Care coordination was identified as another area of need by parents/caregivers, young adults, and health care providers/other stakeholders. Parents/caregivers reported a lack of communication and sharing of information between the PCPs and specialists caring for their child with epilepsy; many expressed frustration at having to do the care coordination themselves. While specialty care providers had a more favorable view of their communication with PCPs than the PCPs did, all providers acknowledged the difficulty of coordinating care for CYE. Participants emphasized the challenges of communicating with other providers who are outside their network or hospital group and who do not use the same electronic health record (EHR) system. Recommendations to improve care coordinating included developing an algorithm or decision support tool to help clarify roles and responsibilities around data sharing and patient follow-up between PCPs and specialists.

Recommendations

Opportunities exist for the National Coordinating Center for Epilepsy and its strategic partners in the field to close existing gaps and leverage resources to improve the provision of coordinated, comprehensive, and quality care for children and youth with epilepsy. Based on the findings of this needs assessment and a strategic planning session with its CYE Advisory Committee, the Center puts forth the following recommendations organized into overarching domains.

Resource Dissemination

Needs assessment findings highlight the fact that health care providers, patients, and families may not know about the wide range of available resources. Stakeholders in the field of pediatric epilepsy note that existing resources must be collated and disseminated to reach the broadest possible audience.

- Conduct an environmental scan to collect and review existing resources related to pediatric epilepsy care.
- Collate existing resources and post on National Coordinating Center for Epilepsy webpages on AAP.org.
- Develop, implement, and evaluate a two-pronged resource dissemination strategy, targeting both health care providers and patients/families in collaboration with internal and external partners.

Education

Results from the needs assessment indicate that education and training is needed to improve numerous aspects of care for CYE. A lack of knowledge and misconceptions about epilepsy exist among the general public and must be addressed.

- Conduct an assessment to determine the types of trainings and educational opportunities which draw the greatest interest and participation among health care providers.
- Collaborate with internal and external stakeholders to develop, implement, and evaluate trainings on communication, culturally competent care, SUDEP, epilepsy diagnosis/treatment, managing epilepsy comorbidities, and care coordination/team-based care, among others, for primary care physicians.
- Encourage more in-depth epilepsy education in medical schools and residency training programs.
- Provide epilepsy-specific training opportunities to allied health professionals, including school nurses, community health workers, and social workers.
- Provide patient/family-focused education through peer-to-peer linkages, support groups, and connection with family-based organizations to support patient/family empowerment, self-advocacy skills, and shared decision-making.

- Develop and promote an epilepsy awareness campaign for the general public to reduce the common misconceptions which continue to perpetuate stigma.

Partnerships

The field of pediatric epilepsy care is comprised of many professionals and organizations working in clinical care, public health, social services, and patient/family advocacy. Improving access to care for CYE needs to be undertaken in a holistic, collaborative manner with all stakeholders involved.

- Connect primary care providers to local resources (eg, AAP chapters, Epilepsy Foundation chapters, and patient/family advocacy organizations) so PCPs can share relevant resources with their patients.
- Facilitate partnerships between clinical practices and non-traditional sites (eg, school-based health centers) to serve as telehealth hubs so patients/families without reliable broadband and hardware can utilize telehealth services.
- Promote the broad integration of mental/behavioral health, advanced practice, and allied health professionals into team-based epilepsy care.

Promoting Health Equity and Culturally Competent Care

Promoting health equity for CYE and providing culturally competent care were identified as areas of need by parents/caregivers, young adults, and health care providers/other stakeholders.

- Review the extent to which health equity principles and cultural competence/humility are incorporated into medical school curricula and residency training programs; assess gaps and develop a plan to improve these aspects of medical education.
- Raise awareness about existing inequities in epilepsy care, especially for infantile spasms and epilepsy surgery, and develop a plan to reduce/eliminate such inequities.
- Promote the need for support services such as interpretation services and cultural advocacy for patients and families whose native language is not English.
- Approach health care transition from pediatric to adult care through a culturally informed lens.
- Ensure materials and resources for patients/families are available in the languages spoken by the communities and populations served.

Addressing System-level Issues

Needs assessment findings and stakeholder discussions point to the demand for increased awareness of system-level issues impacting care for CYE. Recommendations to address such systemic barriers include:

- Create awareness about the importance of a sustainable, consistent payment and reimbursement structure for telehealth, care coordination, as well as the work of advanced practice and allied health professionals.

- Increase awareness of barriers faced by physicians who care for patients with medical complexity; promote efforts to remove such barriers while increasing incentives for physicians caring for medically complex pediatric patients.
- Support equitable access to broadband to reduce disparities in patients'/families' ability to access reliable digital information and ability to utilize telehealth/telemedicine when appropriate.

Research

While a great deal of information was gleaned from the needs assessment, there remain opportunities to learn more about what is required to support the care of CYE.

- Conduct additional research to better understand the epilepsy care experiences of patients and families identifying as racial/ethnic minorities and those living in rural communities.
- Undertake a project to better understand what happens before epilepsy diagnosis to determine why patients/families experience challenges obtaining diagnosis.
- Conduct a study to determine the barriers to and opportunities for increasing team-based epilepsy care.
- Conduct additional research on the future of telehealth to determine how best to support both physicians/health care professionals caring for CYE and CYE patients/families going forward.
- Undertake a study to determine the epilepsy care needs of children and youth with medical complexities and/or multiple comorbidities.

Limitations and Conclusion

Limitations

This needs assessment contained a few limitations. First, the limited geographic and racial/ethnic diversity among parent/caregiver and young adult respondents restricts the generalizability of the findings to rural and non-White populations. Although the Center engaged in broad recruitment efforts, it did not receive a high response rate from rural or Black, Hispanic, Asian, and/or Native American parents/caregivers and young adults, thereby limiting participation in both the quantitative and qualitative aspects of the needs assessment to a relatively homogeneous convenience sample. Targeted outreach to rural and non-White populations will be helpful in future iterations of this work. Second, the needs assessment was only conducted in English which hindered the ability of the Center to reach populations for whom English is not the primary language. Future needs assessments should include translated survey instruments and bi-lingual focus group facilitators. Third, the needs assessment did not include questions about children and youth with epilepsy with medically complex cases and multiple comorbidities. Additional questions about rare epilepsies, medical complexities, and comorbidities should be included in future pediatric epilepsy-focused needs assessments. Finally, despite extensive recruitment, the AAP member and general health care provider participation in the needs assessment was low, which may have been impacted by the competing priorities due to the COVID-19 pandemic. Health care provider experiences with epilepsy care should be examined again once the burdens of the ongoing pandemic have receded.

Conclusion

The needs assessment as conducted by the National Coordinating Center for Epilepsy utilized a mixed methods approach to collect a great deal of data from parents and caregivers of children and youth with epilepsy, young adults living with epilepsy, primary care and specialty care physicians, and additional stakeholders. This information learned through this needs assessment will be used to drive a strategic agenda for both the Center and the field of pediatric epilepsy care at large. The strategic agenda will complement the mission of the Center in supporting professionals working to improve access to coordinated, comprehensive, and quality care for children and youth with epilepsy. The Center thanks all who participated in this needs assessment for sharing their experiences, insights, and recommendations as related to this very important work.

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Appendices

1. Appendix A – AIM-ET Project Surveys
2. Appendix B – Needs Assessment Parent/Caregiver Survey
3. Appendix C – Needs Assessment Young Adult Survey
4. Appendix D – Needs Assessment AAP Member Survey
5. Appendix E – Needs Assessment Focus Group & Key Informant Interview Scripts
6. Appendix F – Quantitative Data Analysis
7. Appendix G – Qualitative Data Analysis, Executive Summary

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