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The IMPACT Epilepsy Consortium: Exploring Social Drivers of Health in Epilepsy Care to Advance Solution Based Initiatives

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Highlights

1. Social needs are highly prevalent among people with epilepsy.
2. Providers report inconsistent screening in clinical settings.

3. Gaps exist for addressing social drivers of health in routine epilepsy care.
4. Patient and provider perspectives on care barriers require improved alignment.
5. Stakeholder-engaged approaches can improve equity in epilepsy care.

Abstract

Rationale: Social determinants of health (SDOH) are increasingly recognized as critical drivers of disparities in epilepsy care, yet systematic approaches to identifying and addressing social needs in clinical settings remain limited. The IMPACT Epilepsy Consortium conducted pilot surveys to characterize SDOH challenges faced by people with epilepsy (PwE) and the perspectives of clinicians who provide epilepsy care.

Methods: Two REDCap-based digital surveys were distributed nationally: one to healthcare providers across epilepsy specialties and another to PwE and caregivers. Surveys assessed perceived social needs, barriers to care, screening practices, and lived experiences relevant to SDOH.

Results: A total of 113 epilepsy providers and 112 community respondents participated.

Providers most commonly identified transportation limitations, rural residence, behavioral health needs, and financial instability as key barriers affecting epilepsy care. Screening for social needs was inconsistent. Community respondents reported substantial unmet needs, including food insecurity, housing instability, transportation challenges, and difficulties navigating healthcare systems. Nearly one-third reported that providers never asked about social needs, and many described limited support in addressing barriers. Open-ended responses highlighted five major **content categories**: access to care, transportation burden, loss of autonomy and social isolation, mental health challenges, and distrust or negative experiences with healthcare providers.

Discussion: Findings reveal misalignment between provider awareness of SDOH and consistent action to address them, underscoring the need for standardized screening, improved care coordination, and expanded community-engaged strategies. The goal of the IMPACT Consortium is to develop pathways to reduce disparities and strengthen clinic-to-community support for PwE.

1.0 Introduction

There are over 50 million people with epilepsy (PwE) worldwide, many of whom experience significant economic, social, and quality-of-life burdens. Over the past decade, there has been increased interest in investigating the role of the social determinants of health (SDOH) on epilepsy prevalence, care, and outcomes. There is now substantial evidence demonstrating that PwE from socioeconomically disadvantaged backgrounds experience higher disease burden, barriers to care, and increased mortality [1-4], **with key SDOH influencing epilepsy care and outcomes** including lower education [5, 6], lower occupation [6], insurance type [1, 3, 7], and neighborhood-level deprivation [8-10]. **Among SDOH**, social needs represent patient-identified priorities within social risk factors that can have an immediate impact on health outcomes and are central to shared decision-making and treatment [11]. More than 45% of PwE report moderate to significant social needs [12], with overall levels of need higher among PwE than among individuals without epilepsy [13]. These social needs include food insecurity, economic hardship, transportation needs, social isolation, and inadequate access to care [12-15].

Ensuring optimal health for PwE requires addressing systemic barriers and social needs. The multidisciplinary IMPACT Epilepsy Consortium (Initiatives for Mobilizing Equitable Patient Access, Care and Treatment in Epilepsy) formed in 2024 to engage partners and advance

efforts towards alleviating prevalent disparities in the care of PwE across the lifespan [16].

Pertinent to the objectives laid out by IMPACT was the ability to meaningfully survey the epilepsy community to better understand challenges inherent to the delivery of epilepsy care to the full spectrum of patients across sociodemographic and geographic variables. Beyond this central purpose, the efforts to engage both providers and patients was intended to serve as a baseline for identifying challenges in reaching the spectrum of PwE, inclusive of those with highest social needs further impacted by systemic barriers. Further, directly engaging multilevel stakeholders can help identify knowledge gaps, including areas where PwE and provider perspectives on the preferences and priorities surrounding social needs may differ.

The aims of this manuscript are to 1) present pilot survey data examining community and provider perspectives on the most prevalent social needs impacting PwE, 2) identify challenges in accessing a complete scope of individuals who seek comprehensive care for their epilepsy and resources for social needs, and 3) provide recommendations for improving the quality of engagement and action across the broader epilepsy community.

2.0 Methods

2.1 IMPACT Epilepsy Consortium

The IMPACT Epilepsy Consortium (Figure 1) includes multidisciplinary clinician scientists who represent epilepsy centers at academic institutions (Cleveland Clinic, Dartmouth College, University of Alabama, University of California Davis, University of Wisconsin, Washington University) across the United States. This strategic partnership was formed with the intention of collaborating to accelerate the focus and action around disparate care and outcomes experienced by PwE as a means to improving health equity in epilepsy. The Consortium employs (1) bridging clinic and community-centered approaches to identify social and structural factors shaping access to epilepsy care, and (2) engaging a spectrum of stakeholders including PwE, care partners and families, clinicians, community based

organizational leaders, professional societies and advocates. Findings from surveys, open forums with facilitated discussion, advocacy training, and scholarly dissemination will guide the co-development of practical resources and innovative tools that support individuals and communities for localized engagement and scalable impact.

2.2 Pilot SDOH Survey Development

The IMPACT Epilepsy team designed two unique digital surveys using the Research Electronic Data Capture (REDCap) [17, 18] to collect voluntary self-reported participant survey data for two groups: (1) a representative group of health care providers that provide care to PwE; and (2) a community cohort of individuals impacted by epilepsy (inclusive of PwE and caregivers of PwE). Survey questions were clustered into key thematic areas relevant to each respondent group. The iterative development of the surveys was guided by multidisciplinary epilepsy center providers and informed by prior literature on SDOH in PwE. The survey development team included individuals with lived experience with epilepsy, who contributed to item generation, wording, and review of the final instrument to ensure relevance to patient priorities and accessibility across literacy levels. Prior to dissemination, organizational leaders from the partner epilepsy organizations involved in survey distribution were given the opportunity to review the survey and provide feedback. Instrument validity was further established by engaging with epilepsy specialty subject matter experts who were asked to verify that the survey questions were relevant to the study aim (face validity) and that the survey comprehensively covered all aspects of the study aim (content validity). The experts responded with minor recommendations for clarity. The survey was edited per expert suggestions and disseminated electronically via REDCap.

2.3 Setting and Participants

Participants for the provider survey were recruited through professional organizations (e.g., American Epilepsy Society, American Academy of Neurology, International Neuropsychological Society) and via a survey link that was distributed to colleagues within Consortium members' clinical and research networks across the United States. Study investigators contacted epilepsy clinic leaders via an email message describing the project and inviting them to distribute the survey invitation to their epilepsy center colleagues, to include individuals who held clinical provider roles working closely with PwE and involved in providing clinical services to PwE. Potential respondents were asked to fill out a one-time voluntary electronic survey sharing their experience and perceptions of the SDOH that most impact epilepsy in their patients. Recruitment relied upon a snowball sampling method to reach networks not immediately available to the researchers,

The community survey distributed to PwE and caregivers was disseminated through epilepsy community and service organizations in the United States via social media platforms and newsletters. The community survey presented respondents with a lay definition of SDOH to assist with survey literacy prior to engaging them with primarily multiple-choice questions, most without a required response. A single open response query allowed for additional feedback to be provided by respondents. Upon completion of the survey, respondents were provided with a list of relevant resources to ensure support following disclosure of unmet needs. Items screening for SDOH were adopted and modified from the Centers for Medicare & Medicaid Services (CMS) Accountable Health Communities Health-Related Social Needs Screening Tool [19].

2.4 Study Procedures

All study procedures were approved by the Dartmouth Health Institutional Review Board. The development and conduct of the research were guided by an expert panel of multidisciplinary epilepsy clinician scientists and public health professionals.

2.5 Analyses

Descriptive statistics for quantitative survey data were conducted using R version 4.3.3 [20].

Open-ended survey responses were reviewed in two stages. First, one member of the study team (AR) conducted an initial review of all responses and grouped them into descriptive content categories based on the topics raised by respondents. The full study team then reviewed the categorized responses together in group meetings, discussing each category and collectively selecting illustrative quotes to convey the range and substance of participant responses. This structured review and categorization process was not intended as a formal qualitative analysis.

3.0 Results

3.1 Clinician Respondents

The sample included n=113 providers (Table 1), most of whom identified as Non-Hispanic White and female/woman. The most common specialties represented were epileptologists (32.7%), neuropsychologists (24.8%), and neurologists (17.7%). Years in practice were distributed across career stages, with the largest groups being those with >20 years (25.7%). Providers primarily practiced in urban settings (75.2%), with additional representation from suburban (20.3%) and rural (23%) environments, with some providers practicing in multiple settings. Most providers reported caring for adults (84%), with nearly half indicating their practices serve geriatric patients (46%) and roughly a quarter caring for pediatric patients (27.4%). The most common states of practice were Ohio (18.5%), New Hampshire (15.9%), California (10.6%), and Missouri (10.6%). Most respondents primarily cared for adults (84%), while nearly half also served geriatric populations (46%) and over one-quarter treated pediatric patients (27.4%). On average, epilepsy made up the majority of their clinical practice, and providers reported caring for notable proportions of patients living in rural areas (26.78%), from

underserved minoritized backgrounds (23.24%), with incomes below the federal poverty line (21.98%), and with disabilities (24.83%).

3.2 Clinician Responses to SDOH Survey

The provider survey assessed healthcare professionals' perspectives on the SDOH affecting PWE, including access, patient-level, and cost-related barriers, along with provider demographics, practice characteristics, screening practices, and approaches to addressing social needs in epilepsy care. Regarding access barriers, providers endorsed transportation (96.5%), living in rural areas (60.2%), and accessing specialty care (50.4%) as the top three barriers impacting epilepsy care (Figure 2A). Regarding patient-level barriers, providers endorsed behavioral and mental health needs (86.7%), social support (77.9%), and health literacy (64.6%) as the top three barriers impacting epilepsy care (Figure 2B). Regarding cost barriers, providers endorsed financial instability (83.2%), insurance coverage (78.8%), and medication coverage (64.8%) as the top three barriers (Figure 2C). Cost factors (38.4%) were endorsed as the top barrier, followed by access (34.8%), and patient-level barriers (26.8%; Figure 2D). Access to medical and surgical treatment and treatment adherence were the most commonly reported patient care factors impacted by SDOH (Table 2).

As a sensitivity analysis, we examined differences in barriers endorsed by providers who care exclusively for pediatric patients (n = 18, 15.9%) compared to those who care exclusively for adult or geriatric patients (n = 82, 72.6%). Fisher's exact tests revealed that pediatric providers were more likely to endorse immigration status (16.7% vs. 1.2%, p = .018), parent or caregiver health literacy (77.8% vs. 23.2%, p < .001), and childcare (38.9% vs. 15.9%, p = .046) as barriers to care. Conversely, adult and geriatric providers were more likely to endorse patient health literacy as a barrier (67.1% vs. 38.9%, p = .003).

3.3 Provider practices related to social needs screening and care coordination

Providers endorsed screening for social needs “All of the time” (38.9%) or “Some of the time” (37.2%); while most providers endorsed addressing social needs “Some of the time” (15.9%) (Figure 4A; Table 2). Most providers noted that they were “Not sure” (46%) if their clinics systematically screened for SDOH (Table 2). When asked who should be responsible for screening and addressing SDOH, most respondents reported social workers (82.3%), primary care providers (69.9%), and epileptologists (66.4%; Table 2). The most common strategies used to address social needs included referral to social work (86.7%) and community-based resources (75.2%; Table 2).

3.4 Community Respondents

The community sample included a total cohort of n=112 individuals impacted by epilepsy (inclusive of PwE and caregivers of PwE; Table 3). Most respondents self-identified as Non-Hispanic White, were women, and had some level of college education. Most respondents were either on disability or unable to work due to epilepsy. Household size ranged from 1 to 6 and household income ranged from \$10,000 to \$280,000. Most respondents with epilepsy had seizures for more than 20 years, were on Medicaid/Medicare, were receiving their epilepsy care at an epilepsy center, and had to travel more than 50 miles to receive epilepsy care. The survey lacked an item explicitly asking if the respondent was a PWE or care giver (see Limitations).

3.4 Community (Patient and Caregiver) Responses to SDOH Survey

3.4.1 Housing and Food Insecurity

Most respondents reported stable housing, though 8.9% were worried about losing housing and 5.4% lacked a steady place to live. Food insecurity was reported by 20.6% of respondents, with 15.2% indicating it was sometimes true and 5.4% often true. Nearly one-third lacked reliable transportation, and 8.0% experienced threats of utility shut-off. Forty-two percent reported difficulty affording basic needs. See table 3.

3.4.2 Health Literacy and Language Barriers

Almost half of respondents reported never receiving health literacy support (43.8%). In contrast, 19.6% respondents indicated that health literacy support was always provided, while 8.0% reported often receiving such support. Intermittent support was reported by 13.4% respondents who received support occasionally and by 15.2% respondents who received support sometimes. Additionally, 5.3% respondents reported difficulty understanding health information because it was not provided in their preferred language. See table 3.

3.4.3 Barriers to Epilepsy Care

The top five barriers to receiving healthcare endorsed by respondents included long wait times for appointments (34.8%), difficulties with transportation to appointments (30.3%), negative past experiences with healthcare providers (25%), difficulty scheduling appointments (23.3%), and cost of healthcare services (22.3%; Figure 3A).

3.4.4 Endorsed barriers by income and education level

As a sensitivity analysis, we stratified participants by household income relative to the 2024 U.S. median (\$83,730). Of the 74 participants who provided income data, 55.4% reported household incomes below the national median and 44.6% reported incomes at or above it. Differences in endorsed barriers between the two groups were examined using Fisher's exact tests, with the percentage endorsing each barrier shown in Figure 5. Provider availability differed significantly between groups: participants with incomes below the national median were more likely (29.3% versus 0%) to endorse "few epilepsy providers nearby" as a barrier to care (Fisher's exact test, $p < .001$).

We also examined differences in endorsed barriers between individuals with less than a bachelor's degree (45.9%) and those with a bachelor's degree or higher (54.1%); see Figure 5. Two barriers differed significantly between groups. Healthcare cost was endorsed as a barrier more frequently by participants with a bachelor's degree or higher (32.2% vs. 8.0%, $p = .002$),

while difficulty understanding medical information was more often endorsed by participants with less than a bachelor's degree (20.0% vs. 6.8%, $p = .048$).

3.4.5 Patient and Caregiver Experience with SDOH Screening and Resource Assistance

Respondents reported considerable variability in how often their healthcare providers asked about social needs (Figure 4B). Nearly one-third (30.4%) indicated their providers never asked about these needs, while others reported being asked rarely (20.5%), occasionally (16.1%), or some of the time (27.7%).

Respondents reported receiving help with navigating healthcare from a variety of sources, though high levels of support were endorsed by relatively few participants (Figure 3B). The top sources of support to address social needs and challenges included epileptologists (38.4%), primary care providers (27.7%), web-based information (22.3%), and neuropsychologists or psychologists (18.8%). A significant proportion of respondents reported that they received no help from any source (25.9%).

3.5 Open Response Data in Community Survey

Participants were also asked in a single open-question format for additional details or examples of how these challenges impacted their healthcare experience. Forty-five (40.2%) of the 112 respondents included a lived experience or general reflection. After reviewing the open-ended responses provided by survey participants, we identified five major **content categories** including access to care, transportation, loss of autonomy and insufficient support networks, stress and mental health challenges, and distrust and negative experience with medical providers and healthcare systems.

First, respondents described difficulty with access to care, including affording and obtaining antiseizure medications, finding mental health services, and limited health insurance coverage.

“Insurance does not cover needed meds so I go to international pharmacy, I don't go to doctors because it is so hard to get an appointment, they are rushed and don't seem to care” P38 (69-year-old white woman with 18 years of education).

“There is always shortages of medicines like Onfi.” P27 (38-year-old white man with 16 years of education)

“I do not have medical insurance. [Imagine] the situation.” P6 (55-year-old Hispanic woman with a doctoral degree)

“Finding Child Life Services or counseling is the hardest hurdle” P3 (39-year-old white woman with some college)

Second, distance travel was another common theme, with respondents having to travel significant distances to see their neurologist/epileptologist or access a pharmacy.

“No Epileptologist available within 50 miles” P25 (68-year-old man with some college)

“Transportation to an epilepsy center is difficult - 60 miles away.” P33 (White man with some college)

“Obtaining medicine is a terrible experience. So many pharmacies have been shut down in my area that I have to travel (w/o a car) many miles to a difficult pharmacy.” P27 (38-year-old white man with 16 years of education)

Third, respondents described a loss of autonomy and a reliance on, or lack of, support networks. Participants noted experiences such as job loss, inability to work or live independently, dependence on family to navigate healthcare tasks, and insufficient support to manage their care. Several also emphasized social isolations related to seizures and the associated restrictions on daily activities (e.g., driving).

"I'm 53 and I have my mom helping me with everything after I lost my job because of seizures" P15 (53-year-old white man with some college)

"If it weren't for help from [my] family, I would be homeless." P16 (45-year-old woman with 16 years of education)

"Lack of available caregiver to attend appointment," P19 (39-year-old white woman with less than high school education)

"Social isolation because cannot drive." P40 (60-year-old white woman with some college)

One participant reported isolation from both the epilepsy community and his social environment, noting not feeling safe to disclose his epilepsy diagnosis to friends and acquaintances.

"Isolation from both the epilepsy community as well as personal social interactions (no one knows I have epilepsy - it doesn't feel safe to tell any of the[m]- the offhand jokes made about epilepsy contribute to this - it's not emotionally safe to tell friends and/ or acquaintances about my having epilepsy" P17 (67-year-old white man with some college)

Fourth, respondents endorsed stress and other mental health challenges associated with managing their condition.

"It's a constant struggle & makes me overwhelmed." P18 (46-year-old white woman with vocational training)

"The frustration is overwhelming sometimes. I have family support but that makes me feel guilty for always depending on them." P30 (White woman with a high school education)

“Managing stress is critical to managing my epilepsy and those things are rarely covered by insurance.” P20 (42-year-old white woman with a Master’s degree)

“they usually make me very confused and depressed because I tend to forget a lot of things that I should have included and don’t remember until later. My loss of memory bothers me a lot and not only because of my brain surgeries for brain removal and shunt installed which keeps me with constant pain. My constant loss of memory keeps me with a headache because of the stress that I guess I give myself.” (60-year-old African American woman with some college education)

Fifth, respondents described distrust and negative experiences with medical providers. Some participants reported feeling unheard, unsupported, and invalidated. They also noted providers not dedicating enough time during their visits, not addressing other aspects of their health/lives, and one participant describing epilepsy care existing as silos.

“I often avoid contacting my epilepsy team when my mood is real bad because I don’t want to be labeled. I’ve had horrific experiences with the mental health community shortly after I was diagnosed at age 25.” P13 (54-year-old white woman with some college)

“For years I had a neurologist who never asked me any questions except to remember three names.” P4 (54-year-old white woman with a high school education)

“Doctors tend to medicalize every issue and prescribe medicine instead of teaching you how to adjust your lifestyle” P36 (26-year-old white woman with 16 years of education)

“Healthcare professionals that don't take women seriously. Healthcare professionals that resist consultation when women say their seizures are related to menstrual cycle. When epilepsy care exists in siloes.” P5 (Multiracial Hispanic)

4.0 Discussion

Knowledge around disparities in epilepsy care and outcomes suggests that to address gaps in care, focused effort must be placed on solutions at the point of patient care [21-25]. This requires a comprehensive appreciation for the lived experiences of PWE and the healthcare professionals who diagnose and treat their disease, through a lens that also allows for integration of the insights and capabilities of the epilepsy workforce, community stakeholders and supports [22, 23, 27]. There is a gap in comprehensive epilepsy care related to identifying and managing SDOH, limiting access to care and causing worse health outcomes. Addressing SDOH in PwE is crucial as epilepsy management depends heavily on consistent access to care, medication adherence, safety, and lifestyle stability. The current survey results suggest a pattern where social needs are inconsistently recognized and addressed across epilepsy care settings. A gap in care limits the ability of individuals affected to access, adhere to and benefit from recommended epilepsy care and treatment.

4.1 Epilepsy provider perspectives

In our provider survey, providers identified transportation, rural residence, and access to specialty care as the top access barriers; behavioral and mental health needs, social support, and health literacy as the top patient-level barriers; and financial instability, insurance coverage, and medication coverage as the top cost-related barriers. Overall, cost-related factors were endorsed most frequently as the leading SDOH affecting epilepsy care, followed by access and patient-level barriers. Access to medical and surgical treatment and treatment adherence were the patient care domains most commonly reported as impacted by SDOH.

Survey responses from providers indicate that screening for SDOH occurs inconsistently, with many reporting that screening only happens “some of the time.” Notably, several providers expressed uncertainty about whether their clinics conduct SDOH screening at all. A lack of clarity may contribute to missed opportunities to identify patients' needs. These results are consistent with prior quantitative and qualitative work measuring provider perceptions and readiness to integrate community health workers in epilepsy center care workflow to address SDOH [27, 28], a systematic measure more routinely implemented in other chronic medical illnesses with positive effect [29-31]. Based on survey results, responsibility for screening appears to vary widely across **care settings**, with some reporting social workers as the primary screeners while others identified neurologists or different staff members. Despite SDOH screening practices improving during the past decade [32, 33], the inconsistencies reported suggest a lack of standardized processes in epilepsy, which may result in unmet social needs and gaps in coordinated care for PwE.

4.2 Community lived experiences

Community lived experience shows barriers that are not fully captured through provider reports alone. While providers often prioritize medical management, PwE experiences broader social and logistical challenges that influence their ability to manage their condition. These may include gaps in communication, differences in health literacy, and structural barriers such as limited integration of screening tools into clinical workflows. Lived experience highlights how these factors can affect treatment adherence and access to resources, offering a more comprehensive understanding of patient needs.

Community survey responses provide important insight into how social barriers to epilepsy care are experienced in practice. Participants **endorsed** a range of barriers to accessing care, including long wait times, transportation challenges, difficulty scheduling appointments, negative prior experiences with health care providers, and the cost of services.

Open-ended responses further elaborated on these experiences, capturing challenges related to access and transportation as well as loss of autonomy, insufficient support networks, stress and mental health difficulties, and distrust of medical providers and healthcare systems. These findings indicate that access to epilepsy care is shaped by structural, relational, and system navigation factors that may hinder engagement with care. These experiences complement provider-reported uncertainty around the SDOH screening process, suggesting that when social needs are not systematically addressed, they may remain unaddressed within clinical encounters.

4.3 The misalignment in patient and provider experiences

When considered together, the provider and community survey perspectives reveal a misalignment between recognition of social barriers and consistent action toward addressing SDOH. While providers acknowledge the influence of SDOH on treatment access and adherence, the absence of systematic screening and referral processes may limit translation of awareness into practice. It is possible that some of the healthcare settings represented in our survey lack the infrastructure needed to systematically screen for or address social needs once they are identified. As such, integrating both perspectives allows for a comprehensive understanding of where breakdowns in care occur. The American College of Preventive Medicine recommends that screening should only occur when sufficient systems exist to address identified needs [34]. A recent survey from the American Epilepsy Society SDOH Working Group found that although 69.5% of respondents stated that they are addressing SDOH in their clinical practice, only one-third reported systematically tracking patient outcomes associated with these efforts, and less than half believed their interventions were having a positive impact [35]. Our findings, aligned with prior surveys, show that despite growing efforts to incorporate SDOH assessment and care coordination, major educational, operational, and systemic barriers still prevent its consistent integration into epilepsy care. The emerging

presence of the IMPACT (Initiatives for Mobilizing Equitable Patient Access, Care, and Treatment) Consortium brings opportunities to work across sectors and eliminate silos which have emerged in the delivery of seamless clinic to community epilepsy care [36, 37]. Identifying key social factors that affect access to epilepsy care by actively engaging multilevel stakeholders, including PWE, their families, health care professionals, and organization leaders, through mixed methods and community-engaged approaches will allow for the emergence of tailored contextual solutions across the spectrum of needs.

4.4 Ongoing gaps and needs

Engagement in the community survey was limited. The demographic composition of respondents suggests that the survey disproportionately captured individuals who are White, of higher socioeconomic status, and reside in select states within the United States, a pattern that reflects structural factors influencing survey access and participation, rather than the absence of unmet needs in other groups. Individuals experiencing greater social and economic disadvantage (housing instability, limited internet access, language barriers) may be less likely to be reached through social media and community newsletter distribution methods. These limitations are not unique to our study, as individuals from social and socioeconomic disadvantaged backgrounds are systematically underrepresented in social needs screening within healthcare settings and less likely to receive assistance when screened [38-40]. As such, populations experiencing the greatest social barriers are those least represented in needs assessments intended to inform care delivery. Without intentional strategies to engage underrepresented and marginalized communities, assessments of social drivers of health risk may reinforce existing inequities by privileging the experiences of those with greater access to health care systems.

One of several thematic areas where resources exist to immediately support PWE is health literacy. Approximately, 43% of PWE who participated in the survey indicated never

receiving support around health literacy. For almost two decades it has been known that lower health literacy is associated with lower quality of life for PWE [41]. Multiple avenues of resource support on this front exist through the social service organizations in the community [42-44] and through national non-profit epilepsy groups. Further, the Centers for Disease Control and Prevention developed and tested several evidence-based epilepsy self-management programs that serve to educate and support PWE, and are broadly accessible through telehealth at no cost [45]. These programs provide education and empower people around their health challenges. Their underutilization requires collaborative action to ensure timely access given the bandwidth for education to be provided during clinical encounters will continue to be limited. Addressing engagement gaps will require alternative outreach strategies to ensure that future efforts accurately reflect diverse experiences within the epilepsy community. Traditionally as a research community, we have aimed to capture feedback from PWE through dissemination of surveys that are distributed in care settings or through a top layer community approach, targeting distribution via known social service organizations where large groups of people are connected. Collectively, this discounts the importance of reaching groups who may not already be connected to community support. There has been a relative paucity of work that explores a more comprehensive assessment of barriers encountered by vulnerable epilepsy patient populations from across diverse settings to participate in community research that is inclusive of survey or other feedback mechanisms. A rethinking of outreach beyond reliance on the status quo community groups and professional societies, and usual methodologies will be required to see improvements. A requirement in the design and implementation of new initiatives to improve inclusivity is a clear understanding of the barriers encountered by individual patient groups. Further considerations must also be given to institutional commitments and funding initiatives that propel this important work. There is a general consensus based on more than a decade of data presented by public health epidemiological studies that disparities, barriers and access

influencing outcomes are highly prevalent in epilepsy [21, 46]. Additional studies are warranted to examine the health inequities associated with race and ethnicity and SDOH by epilepsy status. The resources to improve and accelerate our understanding of social needs drivers and remedies will require investment across several fronts, and existing frameworks and epilepsy center process models that promote systematic approaches should be considered and replicated when possible [23].

4.5 Limitations

Limitations to the community survey occurred when trying to engage a full spectrum of individuals affected by epilepsy. The survey included individuals affected by epilepsy, inclusive of people with epilepsy and caregivers; however, respondent type could not be reliably distinguished due to the absence of an explicit survey item. Interpretation of these results is also limited by demographic homogeneity as discussed above. In-depth, rich exploration of stakeholder experiences and insights around SDOH may not be completely reflected in a quantitative digital survey. Survey design and analytical approach for open-ended responses were not intended as a formal qualitative study, which limits the depth of interpretation. To this end, follow up qualitative feedback will have the potential to deepen our understanding of the lived impact of disparities and inform initiatives focused on closing practice gaps in diverse practice settings.

5.0 Conclusions

The IMPACT Consortium represents a model for bringing together invested groups of epilepsy stakeholders to strengthen connections between clinical care and community-based programs and fosters collaboration among public health practitioners and epilepsy health and social service providers. The current effort to survey epilepsy providers and PWE in the community highlights the challenges of relying on current methodologic approaches for gathering social

needs data that is comprehensive and thereby actionable across epilepsy centers to serve diverse groups of PWE.

Figure Legends

Figure 1: The IMPACT Epilepsy Network is **comprised of** seven epilepsy centers across the United States.

Figure 2: Providers' perceptions of most common barriers among people with epilepsy, including A) access barriers, B) patient-level barriers, and C) cost barriers. D) Providers endorsed the top barrier impacting epilepsy care.

Figure 3: Community survey results. A) Healthcare access barriers endorsed by PwE. B) sources of support for addressing social needs and challenges endorsed in panel A.

Figure 4: Frequency of A) provider screening for social needs and B) patient-reported frequency of being asked about social needs.

Figure 5. Barriers endorsed by income and education level. A) Barriers endorsed by community survey respondents stratified by household income (below the U.S. median of \$83,730 vs. at or above the median). B) Barriers endorsed by community survey respondents stratified by educational attainment (less than a Bachelor's degree vs. Bachelor's degree or higher).

Asterisks indicate statistically significant differences between groups.

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AR: Conceptualization, data curations, formal analysis, investigations, methodology, project administration, resources, software, supervisions, visualization, writing original draft.

MO: Conceptualization, data curations, formal analysis, investigations, methodology, visualization, writing review and editing.

JPW: Conceptualization, data curations, formal analysis, investigations, methodology, visualization, writing review and editing.

EF: Conceptualization, data curations, formal analysis, investigations, methodology, visualization, writing review and editing.

FDL: Conceptualization, data curations, formal analysis, investigations, methodology, visualization, writing review and editing.

TOC: Conceptualization, data curations, formal analysis, investigations, methodology, visualization, writing review and editing.

BPH: Conceptualization, data curations, formal analysis, investigations, methodology, visualization, writing review and editing.

ETK: Conceptualization, data curations, formal analysis, investigations, methodology, project administration, resources, software, supervisions, visualization, writing original draft.

Table 1: Provider Survey Sample Characteristics	
N	113
Race	
White	74 (65.5%)

Asian	13 (11.5%)
Black/African American	9 (7.9%)
Native American or Alaskan Native	1 (<1%)
Middle Eastern or North African (MENA)	3 (2.6%)
Multiracial	3 (2.6%)
Unknown	6 (5.3%)
Ethnicity: Hispanic	13 (11.5%)
Sex/Gender: Female/Woman	72 (63.7%)
Specialty	
Epileptologist	37 (32.7%)
Neurologist	20 (17.7%)
Epilepsy Nurse	2 (1.7%)
EEG Technician	9 (7.9%)
Advanced Practice Providers	13 (11.5%)
Neuropsychologist	28 (24.8%)
Psychologist/School Psychologist	1 (<1%)
Other	3 (2.6%)
Years in practice	
<5	24 (21.2%)
5-9	25 (22.1%)
10-14	25 (22.1%)
15-19	10 (8.9%)
>20	29 (25.7%)
Most common states of practice	
Ohio	21 (18.5%)
New Hampshire	18 (15.9%)
California	12 (10.6%)
Missouri	12 (10.6%)
Pennsylvania	8 (7.1%)
Practice setting	
Urban (i.e., metropolitan areas)	85 (75.2%)
Suburban (i.e., healthcare facilities and environments located in suburban areas)	23 (20.3%)
Safety net (i.e., settings that provide healthcare for individuals regardless of their insurance status)	16 (14.1%)
Rural (i.e., environments located in sparsely populated or remote areas)	26 (23%)
Practice population	
Pediatrics	31 (27.4%)
Adults	95 (84%)
Geriatrics	52 (46%)

Average percent practice is epilepsy	69.31 (30.63)
Epilepsy practice patient characteristics	
Percent living in rural areas	44.41 (26.78)
Percent underserved minorities	37.74 (23.24)
Percent have income below federal poverty line	39.06 (21.98)
Percent persons with a disability	49.28 (24.83)
Percent identify as sexual and gender minority	14.12 (12.26)

Table 2: Provider Practices and Perspectives Related to Social Needs in Epilepsy Care	
Domain	Frequency
Areas of SDOH Impact	
Treatment access- medical	104 (92%)
Treatment access-surgical	86 (76.1%)
Treatment adherence	99 (87.6%)
Diagnostic evaluation- outpatient testing	80 (70.8%)
Diagnostic evaluation- inpatient testing	60 (53.1%)
Monitoring treatment effect	69 (61.1%)
Communication with medical team	77 (68.1%)
Attending clinic follow-up visits	85 (75.2%)
Connecting to adjunct community care	71 (62.8%)
Access to epilepsy self-management programs	64 (56.6%)
Frequency of social needs screening	
All of the time	44 (38.9%)
Some of the time	42 (37.2%)
Occasionally	18 (15.9%)
Rarely	4 (3.5%)
Never	4 (3.5%)
Frequency of addressing identified needs	
All of the time	30 (26.5%)
Some of the time	55 (48.7%)
Occasionally	18 (15.9%)
Rarely	7 (6.2%)
Never	2 (1.8%)
Tracking practices within clinic	
Yes	43 (38.1%)
No	17 (15.0%)
Not sure	52 (46.0%)
Perceived responsibility for addressing SDOH	

Social worker	93 (82.3%)
Primary care provider	79 (69.9%)
Epileptologist	75 (66.4%)
Community health worker	63 (55.8%)
Epilepsy nurse	55 (48.7%)
Population health personnel	52 (46.0%)
Neuropsychologist	47 (41.6%)
School psychologist	32 (28.3%)
Pharmacist	23 (20.4%)
PT/OT/Speech therapy provider	14 (12.4%)
Responsibility outside healthcare	4 (3.5%)
Other	4 (5.3%)
Strategies used to address social needs	
Refer to social work	98 (86.7%)
Refer to community-based resources	85 (75.2%)
Refer to a community health worker	36 (31.9%)
Connect to financial assistance programs	41 (36.3%)
Connect to transportation support	48 (38.1%)
Connect to medication assistance	44 (38.9%)
Connect to housing assistance	11 (9.7%)
Connect to food assistance	14 (12.4%)
Other strategies	5 (4.4%)

Table 3: Community Survey Sample Characteristics	
N	112
Race	
White	93 (83%)
Asian	1 (<1%)
Black/African American	9 (8%)
Native American or Alaskan Native	--
Middle Eastern or North African (MENA)	1 (<1%)
Multiracial	3 (2.7%)
Unknown	10 (8.9%)
Ethnicity: Hispanic	4 (3.6%)
Sex/Gender	
Man	38 (33.9%)
Woman	70 (62.5%)
Non-binary/non-conforming	1 (<1%)

Prefer not to say	2 (1.8%)
Average age	49.07 (14.73)
Education	
Less than high school	1 (0.9%)
High school diploma or G.E.D.	16 (14.3%)
Vocational or training school	3 (2.7%)
Some college or Associates	29 (25.9%)
College graduate	30 (26.8%)
Master's degree	26 (23.2%)
Doctoral degree	3 (2.7%)
Unknown	3 (2.7%)
Employment status	
Work full time	18 (16.1%)
Work part-time	15 (13.4%)
Self-employed	9 (8%)
Unemployed seeking work	17 (15.2%)
Unemployed not seeking work	5 (4.5%)
Retired	17 (15%)
Unable to work due to epilepsy	24 (21.4%)
Disability	25 (22.3%)
Volunteer	5 (4.5%)
State of residence	
Pennsylvania	25 (25.3%)
Arizona	14 (14.1%)
Colorado	8 (8.1%)
New York	7 (7.1%)
Household size	2.11 (1.22)
Average household income in dollars	92,872.46 (71,249.76)
Seizure duration	
Less than 2 years	3 (2.7%)
2 - 4 years	11 (9.8%)
5 - 9 years	17 (15.2%)
10 - 14 years	13 (11.6%)
15 - 19 years	15 (13.4%)
More than 20 years	52 (46.4%)
Regular/Routine Epilepsy Care Locations	
Clinic at medical center	31 (27.7%)
Epilepsy center	67 (59.3%)
Community/rural health center or FQHC	2 (1.8%)
County hospital	1 (<1%)
Private practice	18 (16.1%)

Emergency Department/Urgent care	4 (3.6%)
None	1 (<1%)
Other	4 (3.6%)
Distance to epilepsy care	
Less than 1 mile	4 (3.6%)
1–4 miles	17 (15.2%)
5–10 miles	22 (19.6%)
11–20 miles	15 (13.4%)
More than 20 miles	20 (17.9%)
More than 50 miles	32 (28.6%)
Living situation	
Steady place to live	95 (84.8%)
I have a place to live today, but I am worried about losing it in the future	10 (8.9%)
I do not have a steady place to live	6 (5.4%)
Food insecurity	
Never true	88 (78.6%)
Often true	6 (5.4%)
Sometimes true	17 (15.2%)
Lack of reliable transportation	35 (31.0%)
Utility shut-off risk	9 (8.0%)
Affording basic needs	
Not difficult at all	64 (57.1%)
Somewhat difficult	32 (28.6%)
Very difficult	16 (14.3%)
Health literacy support	
Always	22 (19.6%)
Often	9 (8.0%)
Occasionally	15 (13.4%)
Sometimes	17 (15.2%)
Never	49 (43.8%)
Language barrier	6 (5.3%)
Insurance type	
Medicaid/Medicare	53 (47.3%)
Other public insurance	9 (8.0%)
Private Insurance	44 (39.3%)
Uninsured	4 (3.6%)
Feel safe at home	
Yes	81 (77.1%)
No	7 (6.7%)

Unsure	14 (13.3%)
Chose not to respond	3 (2.9%)

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