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When and why US primary care providers do and do not refer their patients with new-onset seizures or existing epilepsy or seizure disorders to neurologists—2018 DocStyles

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Abstract

Monitoring primary care providers' (PCP) attitudes and experiences with referrals of their patients with new-onset seizures or existing epilepsy/seizure disorders may help evaluate whether interventions to coordinate PCP and neurology care reduce treatment gaps and improve patient outcomes. To examine PCPs' attitudes toward, and experiences with, referral to specialty care of their patients with newonset seizures or existing epilepsy/seizure disorders, we used cross-sectional 2018 DocStyles data to examine study outcomes. We selected a subsample of respondents who had a practice with at least 1% of patients with an epilepsy/seizure disorder and who answered questions about this disorder. We stratified provider actions, referral behavior, and referral enabling factors and barriers by epilepsy/seizure disorder caseload and provider

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Appendix A. Supplementary data

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type. We examined different patterns of responses by referral behavior and provider type. The final sample (n = 1284) included 422 family practitioners, 432 internists, 233 pediatricians, and 197 nurse practitioners. Most PCPs refer their patients with new-onset seizures to a neurologist, particularly to determine or confirm the diagnosis and appropriate treatment. Strikingly, about 40% of PCPs did not indicate a referral if their epilepsy/seizure disorder patient was unresponsive to treatment. Internists less likely referred their patients than pediatricians, nurse practitioners, or family practitioners. Less than one-third of all practitioners consulted seizure treatment guidelines. Prompt appointments, communication with the PCP, the patient's insurance, and referral back to primary care may facilitate referrals. Interventions that enhance enabling factors for guidelines-based care and that can increase opportunities for PCPs to consult with neurologists and/or refer their patients with uncontrolled seizures to specialty care are warranted.

Keywords

Epilepsy; Seizures; Referrals; Specialty care

1. Introduction

About 3 million US adults have active epilepsy (self-reported doctor diagnosed epilepsy under treatment or with recent seizures) [1]. About 80% of these adults have seen a general practitioner in the past year but fewer saw a specialist [2]. Although most people with epilepsy respond to anti-seizure medications under the care of a general practitioner, about 30% of people with epilepsy in clinical settings to 50% in community settings continue to have seizures [3–5]. In 2010 and 2013, 23% of US adults with treated active epilepsy reporting at least one seizure in the past year saw only a general practitioner [6]. Adults with uncontrolled epilepsy have increased risks of multiple adverse health and social outcomes and early death [5]. Consistent with epilepsy clinical practice guidelines, referring these individuals for specialty care with a neurologist or epilepsy specialist is critical to ensure proper diagnosis and treatment [5]. A few studies have identified attitudes about, and barriers to specialty care referral at the patient level (e.g., age; nature or complexity of the presenting problem); provider level (e.g., provider training and experience; inter-physician communication); and community level (e.g., overall availability of specialists) [7–11]. This study aimed to understand when and why US primary healthcare providers are likely to refer their patients with new-onset seizures or existing epilepsy or seizure disorders to a neurologist.

2. Methods

2.1. Design and participants

We used the 2018 DocStyles-A survey, the first of two annual nationwide cross-sectional web-based surveys developed by Porter Novelli with input from public agencies and private groups designed to assess healthcare providers' knowledge, attitudes, and experiences with health issues and healthcare practice [12]. The 2018 provider sample was drawn from an opt-in panel of medical professionals who registered with SERMO, a free global social network of > 550,000 US medical professionals, and SERMO panel partners described

elsewhere [13]. Porter Novelli set survey sample size quotas for different providers of focus (e.g., target quota of 1,000 family and general practitioners, and internists; 250 nurse practitioners), and SERMO sent e-mails inviting participation in DocStyles-A to 3,465 PCPs (family and general practitioners, internists), nurse practitioners, pediatricians, and other providers (e.g., pharmacists, oncologists) who have practiced for at least 3 years. Respondents received \$40-\$90 based on the number of questions asked of their specialty. DocStyles-A contained 141 questions covering providers' demographic characteristics, practice characteristics (e.g., main work setting, years of practice, average number of patients seen weekly, awareness of clinical guidelines), and multiple health topics. Five questions assessed providers' experiences with referring their patients with new-onset seizures and epilepsy or seizure disorder ("epilepsy/seizure disorder") to a neurologist (Table 1). Response rates for DocStyles-A averaged 65% but varied by provider type [12].

2.2. Standard protocol approvals, registrations, and patient consents

Patients were not included in this study, so patient consent and study registration were not required. CDC licensed these data from Porter Novelli Public Services (PNPS). PNPS and its vendors are not subject to CDC IRB review. PNPS adheres to professional standards set forth by the Council of American Survey Research Organizations. Respondents are informed that their answers are used for market research and they may refuse to answer any question. No personal identifiers are included in the data file that is provided to CDC.

2.3. Analysis

We used SAS, version 9.4 (SAS Institute, Inc., Cary, NC) for all statistical analyses. We restricted our analysis to family practitioners, internists, pediatricians, and nurse practitioners, ("Primary Care Providers" [PCPs]). We excluded from analysis particular questions among PCPs who did not answer any of the responses within related epilepsy/seizure disorder questions. We selected respondents who had a practice with at least 1% of patients with epilepsy/seizure disorder and answered subsequent questions on epilepsy/seizure disorder. The 1,284 PCPs who met these study criteria included 432 internists, 422 family practitioners, 233 pediatricians, and 197 nurse practitioners, representing 37% of the survey sample. Among these, the mean age was 49 years (SD = 10.3) with 59.3% being between 40–59 years (Supplementary Table); and 53.8% were male, 46.2% female. Less than 5% of PCPs who saw patients with epilepsy were Hispanic, and only 3.3% of PCPs who saw patients with epilepsy were non-Hispanic black or African-American. Slightly more than one-third resided in the South and close to one-fourth resided in the Northeast. Seventy-two percent practiced in a group outpatient practice. Twenty seven percent have practiced medicine between 3–10 years; 35% between 11–20 years; 29% between 21–30 years; and 9% 31 years (Supplementary Table).

We first stratified each provider action (e.g., diagnosis, guidelines review), referral behavior, and referral enabling factors and barriers by epilepsy/seizure disorder caseload (1%–5%, 6%–10%, 11%) and provider type. We examined each action independently and combinations of these actions, followed by examining referral enabling factors and barriers to identify subgroups who perform only one action (e.g., "only refer,") when deciding to refer, or two or more actions (e.g., "diagnose, treat, review guidelines, and refer"). For combined

responses to the question, “*When a person who visits you develops seizures, what do you do?*” we distinguished respondents *who diagnosed, treated, reviewed treatment guidelines, and referred* (“Manage with guidelines and refer”) their patients to a specialist, from respondents who *diagnosed, treated, did not review treatment guidelines, and referred* (“Manage without guidelines and refer”) their patients to a specialist. Moreover, we identified respondents indicating *only one* enabling factor or barrier by epilepsy caseload and provider type to identify their single most relevant referral-enabling factor or barrier. We considered all estimates to significantly differ if their 95% confidence intervals did not overlap.

3. Results

3.1. Provider actions for new-onset seizure patients — overall and by epilepsy caseload and provider type

When a seizure developed in a PCP’s patient, 90% reported referring the patient to a specialist; 45% would try to diagnose the seizure’s cause; 39% would try to treat the patient; and 29% would review seizure treatment guidelines (Table 2). Forty-three percent would only refer the patient; 15% would manage with guidelines and refer the patient; 10% would manage without guidelines and refer the patient; and 8% would only diagnose and refer the patient.

Seventy-six percent of PCP’s reported a 1%–5% epilepsy caseload; 15%, a 6%–10% caseload; and 9% a 11% caseload (Table 2). PCPs with different epilepsy caseloads equally (40%–51%) tried to diagnose a seizure in their newly diagnosed patients. However, those with an 11% or more caseload more likely treated such a seizure than those with a lesser caseload. Those with an 11% or more caseload more likely consulted treatment guidelines than those with a 1%–5% caseload. Those with a 1%–5% caseload more likely referred patients to a specialist than those with larger epilepsy caseloads (Table 2).

Of practitioners with a 1%–5% caseload, 48% would only refer a patient to a specialist; 14% would manage with guidelines and refer; and 10% would manage without guidelines and refer (Table 2). Of practitioners with a 6%–10% caseload, 30% would only refer their patient to a specialist; 18% would manage with guidelines and refer; and 11% would manage without guidelines and refer. Of practitioners with an 11% or more caseload, 21% would manage with guidelines and refer their patient; 18% would only refer; and 12% would manage without guidelines and refer.

Internists more likely diagnosed their patients with seizures than family practitioners or nurse practitioners, and pediatricians more so than nurse practitioners (Table 2). Internists also more likely treated their patients than family practitioners, nurse practitioners, or pediatricians. All types of practitioners equally (25%–32%) consulted seizure treatment guidelines. Internists less likely referred their patients to a specialist than other PCPs.

Of family practitioners, 47% would only refer their patient to a specialist; 15% would manage with guidelines and refer; 10% would manage without guidelines and refer; 7% would diagnose and refer, while 5% would review guidelines and refer (Table 2). Of

internists, 31% would only refer; 19% would manage with guidelines and refer; 16% would manage without guidelines and refer; and 7% would diagnose and refer; and 3% would review guidelines and refer. Of pediatricians, 46% would only refer; 19% would diagnose and refer; 12% would manage with guidelines and refer their patient; 7% would manage without guidelines and refer their patient; and 3% would review guidelines and refer. Of nurse practitioners, 57% would only refer a patient; 13% would manage with guidelines and refer; 9% would review guidelines and refer; 4% would manage without guidelines; and 3% would diagnose and refer their patient (Table 2).

3.2. Circumstances when a provider would refer a patient with epilepsy/seizure disorder to a neurologist — overall and by epilepsy caseload and provider type

Eighty-two percent of PCPs would refer their patient to a neurologist to determine or confirm a treatment plan; 76%, to determine or confirm a diagnosis of epilepsy or a seizure disorder; 65%, if the patient requested a referral; 64%, if the patient's seizure activity changed; and 56% if the patient did not respond to current treatment (Table 3).

Thirty-five percent of PCPs would refer a patient under any of these circumstances; 11%, only to determine or confirm the diagnosis or treatment plan; 9%, to determine or confirm the diagnosis, to determine or confirm treatment plan, if the patient's seizure activity changed, or if the patient requested a referral; and 7%, to determine or confirm diagnosis, to determine or confirm treatment plan, or if the patient requested a referral (Table 3).

PCPs with a 1%–5% epilepsy caseload more likely referred patients to a neurologist to determine or confirm a diagnosis than PCPs with larger caseloads (Table 3). PCPs with a 1%–5% caseload also more likely referred patients than PCPs with a 11% or more caseload to determine or confirm a treatment plan (86% vs. 72%); if the patient's seizure activity changed (65% vs. 50%); or if the patient requested a referral (68% vs. 50%). All practitioners equally likely (55%–62%) referred a patient if the patient's seizure(s) failed to respond to the treatment plan. Thirty-eight percent of PCPs with a 1%–5% caseload, 30% of those with a 6%–10% caseload, and 18% of those with an 11% or more caseload would refer a patient for any of these reasons.

Pediatricians more likely referred a patient to determine or confirm a diagnosis and to determine or confirm a treatment plan than an internist (Table 3). Internists more likely referred such a patient if the patient failed to respond to current treatment than pediatricians or nurse practitioners. All four kinds of PCPs equally likely referred a patient if that patient's seizure activity changed (58%–69%); if the patient requested a referral (61%–67%), or for any of the specific circumstances mentioned (32%–38%).

3.3. Enabling factors important for referrals of epilepsy/seizure disorder patients to neurologists — overall and by epilepsy caseload and provider type

When deciding to refer, 41% of PCPs considered it important if prompt appointments were available for their patients; 39%, if access to prompts or a referral system; 37%, if they can talk with the neurologist; 35%, if the patient's insurance covered specialty referrals; 31%, if the neurologist returned the patient to them for care; 15%, if the patient lived near to the neurologist; and 17%, indicated none of these factors as important (Table 4). Of PCPs

indicating only a few enabling factors, 8% indicated only access to prompts or a referral system; 5%, only patient insurance status; and 4%, only a prompt appointment or both a prompt appointment and a referral system.

With one exception, PCPs with different caseloads did not differ in how they weighted different referral factors (Table 4). Only practitioners with an 11% or more caseload more likely than those with a 1%–5% caseload considered how near their patient lived to the neurologist's office as an enabling referral factor.

Internists considered whether they could talk to the neurologist as a more important referral factor than other PCPs (Table 4). Patient insurance status was more important for family practitioners than pediatricians, and for nurse practitioners more so than pediatricians. Family practitioners considered whether the neurologist returns the patient to them more important for referral than pediatricians. About one of four pediatricians considered none of the survey factors as important, more so than family practitioners or internists. Only 2%–10% of all PCPs indicated only one referral enabling factor as important.

3.4. Important barriers against referrals to neurologists — overall and by epilepsy caseload and provider type

Of important barriers to referring a patient to a neurologist, 54% of PCPs reported not having access to prompt appointments with a specialist; 40%, lack of patient insurance coverage for a specialty referral; 26%, lack of patient transportation to a specialist's appointment; 16%, a patient's lack of interest in a referral; 4%, uncertainty about where to refer their patients; and 22%, none of the survey items as important barriers (Table 5).

Practitioners with an 11% or more caseload more likely indicated that their patients were not interested in a referral than practitioners with a 1%–5% caseload (Table 5). Practitioners with a 1%–5% caseload more likely than those with larger caseloads considered none of the survey barriers as relevant for referrals. PCPs were similar in how often any single referral barrier was important for them. Pediatricians less likely reported than family practitioners or nurse practitioners that their patient's insurance or lack of transportation were referral barriers (Table 5). Lack of patient interest as a barrier was lower for pediatricians than internists and family practitioners. Internists more likely reported that their patients were not interested in a referral than pediatricians or nurse practitioners. Between 16%–30% of PCPs reported none of the barriers were relevant, with pediatricians being more likely to report this than family practitioners.

4. Discussion

The American Academy of Neurology and other groups publish epilepsy clinical practice guidelines to improve patient care and outcomes and identify when a person with epilepsy should be referred to a specialist (e.g., at diagnosis or failure to respond to treatment) [14–18]. We found that 90% of PCPs indicated that they refer their patients with new-onset seizures to a neurologist, particularly to determine or confirm the diagnosis and appropriate treatment. Of concern, however, about 40% of PCPs did not indicate that they would refer their patient to a neurologist when their existing epilepsy/seizure disorder patients fail

to respond to treatment or has a change in seizure activity. The National Association of Epilepsy Centers' guidelines recommend that a PCP refer to a neurologist those patients whose seizures remain uncontrolled within 3 months after beginning an anti-seizure drug, so our study findings indicate a striking disconnect between epilepsy/seizure disorder clinical guidelines and practice warranting intervention [18]. Given their workload PCPs may find it challenging to know about and follow recommendations from the growing number of clinical practice guidelines [19]. To facilitate opportunities for guidelines-based care, incorporating guidelines into electronic health record (EHR) prompts might optimize access to and use of guideline recommendations specific for a clinical situation (e.g., when starting a new anti-seizure drug) [19]. Structured decision aids to help providers and patients make shared decisions also may increase guideline use and patient engagement in care [20].

It was perhaps unsurprising that practitioners who have an epilepsy caseload of at least 11% more likely managed their patients with epilepsy, and less likely referred them to a specialist given their experience in caring for patients with epilepsy and increased experience with epilepsy treatment guidelines. EHR prompts could also target and disseminate clinical guidelines to clinicians who find this information most useful and relevant. For example, PCP subgroups with larger epilepsy caseloads identified by EHRs might be offered specific decision-aids or remote learning support for their types of patients. Electronic consults and referral templates that improve specialists' satisfaction with referral processes can improve their coordination with PCPs [21,22].

Expanding virtual telementoring and case-based learning opportunities through Project ECHO (Extension for Community Healthcare Outcomes) to link PCPs with specialists to provide complex chronic disease care may improve management for patients with epilepsy in primary care [23]. Two ECHO programs targeting both adult neurology and epilepsy, and pediatric epilepsy, increased primary care provider knowledge, confidence, and self-efficacy in managing epilepsy [24,25]. Targeting interprofessional post-graduate fellowship education for PCPs, in collaboration with teaching hospitals or professional medical societies, is another way to raise their skills in providing epilepsy care and referring patients with neurologic disease. For example, the American Academy of Family Physicians sponsors several fellowships after family medicine residency, but not in neurology [26]. Developing neurology fellowship training for PCPs could help disseminate best practice guidelines for managing patients with epilepsy. After such fellowships, such PCPs might serve as informal consultants to less experienced PCPs, help educate others about practice guidelines and therapeutic advances, and provide access to neurology specialists for consultation and referral. Large medical centers could integrate either PCPs into a specialist neurology team or a neurologist into an internist team to improve communication and referral pathways to neurologists since more than one-third of this study's PCPs found talking with a neurologist an important enabling factor for referral. Joint neurologist-PCP rounds and case conferences, and regular reporting of patient outcome data to PCPs could improve learning, reinforce treatment guidelines, and establish shared provider goals that better meet patient needs.

This study has several limitations. First, the survey assessed PCP's experience with patients with "new-onset" seizures and patients with established seizures, so that we could not

determine the timing of provider actions (e.g., whether treatment followed a neurology consult) for new or established patients, potentially overestimating PCPs' (desirable) seizure management actions. Second, combining responses to assess different groupings of provider actions or to identify a single enabling factor or barrier may be insufficient, implying additional research. Third, since the respondents were drawn from an opt-in panel, respondents might be subject to selection bias. Fourth, provider responses are self-reported and may be subject to social-desirability and recall bias. Fifth, data were not weighted to be nationally representative, so results might not be generalizable to all U.S. PCPs. Finally, by excluding early career PCPs with less than three years of practice experience, we may have excluded PCPs with different attitudes about, or experiences with, referring their patients with new-onset epilepsy to specialists. DocStyles data, however, are commonly used to examine PCPs' experiences with other guidelines-based practices including, for example, alcohol screening, physical activity recommendations, hypertension prevention, fall prevention, and sodium reduction to guide intervention [13,27–30].

Specialty referral improves morbidity outcomes and lowers premature mortality [31–33]. Mortality risk in epilepsy is higher than in the general population because of epilepsy-specific risks (e.g., status epilepticus, sudden unexpected death in epilepsy, suicide, accidents), and risk factors more common in epilepsy (e.g., risk behaviors, comorbidity, social determinants) associated with increased mortality [34–40]. Providers need to recognize medication-resistant epilepsy and its comorbidities and to catalyze timely referral to neurologists or comprehensive epilepsy center teams to avoid increased risks for morbidity and mortality in their patients with uncontrolled seizures [33,41]. Technology-enabled interventions, telementoring, and other innovative medical training opportunities that link neurologists with general practitioners may facilitate proper diagnosis, treatment, and referral of individuals with uncontrolled seizures to specialty care but require more study. Monitoring PCP attitudes and experiences with referrals of their new-onset seizure patients or epilepsy/seizure disorder patients may be useful to evaluate whether interventions designed to increase PCP and neurology care coordination reduces treatment gaps and improves epilepsy/seizure disorder patient outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data availability

Porter Novelli can provide access to the 2018 DocStyles data to qualified investigators through a data use agreement.

References

- [1]. Zack MM, Kobau R. National and state estimates of the numbers of adults and children with active epilepsy — United States, 2015. *MMWR Morb Mortal Wkly Rep* 2017;66(31):821–5. 10.15585/mmwr.mm6631a1. [PubMed: 28796763]
- [2]. Kobau R, Sapkota S, Pennell PB, Croft JB. Six in 10 adults with active epilepsy saw a neurologist or epilepsy specialist in the past year, United States, 2017. *Epilepsy Behav* 2020;11(112):. 10.1016/j.yebeh.2020.107348107348.
- [3]. Kwan P, Brodie MJ. Early identification of refractory epilepsy. *New Engl J Med* 2000;342(5):314–9. 10.1056/NEJM200002033420503. [PubMed: 10660394]
- [4]. Tian N, Boring M, Kobau R, Zack M, Croft J. Active epilepsy and seizure control in adults — United States, 2013 and 2015. *MMWR Morb Mortal Wkly Rep* 2018;67(15):437–42. 10.15585/mmwr.mm6715a1. [PubMed: 29672474]
- [5]. Institute of Medicine. *Epilepsy across the spectrum: promoting health and understanding*. National Academy Press, <https://www.nap.edu/catalog/13379/epilepsy-across-the-spectrum-promoting-health-and-understanding>, 2012 [accessed 1 November 1, 2020].
- [6]. Cui W, Kobau R, Zack MM. Among adults with epilepsy reporting recent seizures, one of four on antiseizure medication and three of four not on medication had not seen a neurologist/epilepsy specialist within the last year, the 2010 and 2013 US National Health Interview Surveys. *Epilepsy Behav* 2016;61:78–9. 10.1016/j.yebeh.2016.04.031. [PubMed: 27318431]
- [7]. Moore JL, McAuley JW, Mott D, Reeves AL, Bussa B. Referral characteristics of primary care physicians for seizure patients. *Epilepsia* 2000;41(6):744–8. 10.1111/epi.2000.41.issue-610.1111/j.1528-1157.2000.tb00237.x. [PubMed: 10840408]
- [8]. Bale JF, Currey M, Firth S, Larson R. and the Executive Committee of the Child Neurology Society. The Child Neurology Workforce Study: Pediatrician access and satisfaction. *J Pediatr* 2009;154(4):602–606.e1. 10.1016/j.jpeds.2008.10.021. [PubMed: 19054527]
- [9]. Mehrotra A, Forrest CB, Lin CY. Dropping the baton: specialty referrals in the United States. *Milbank Q*. 2011;89:39–68. 10.1111/j.1468-0009.2011.00619.x. [PubMed: 21418312]
- [10]. Biggerstaff ME, Short N. Evaluation of specialist referrals at a rural health care clinic. *J Am Assoc Nurse Pract* 2017;29:410–4. 10.1002/2327-6924.12480. [PubMed: 28695714]
- [11]. Ackerman SL, Gleason N. Transitioning patients from specialty care to primary care. What we know and what we can do. *J Ambul Care Manage* 2018;41:314–22. 10.1097/JAC.0000000000000253. [PubMed: 29923847]
- [12]. Porter Novelli. *Styles DocStyles Survey*. Porter Novelli Styles, <http://styles.porternovelli.com/docstyles/> [accessed 6 August 2020].
- [13]. Guglielmo D, Murphy LB, Theis KA, Helmick CG, Omura JD, Odom EL, et al. Physical activity assessment and recommendation for adults with arthritis by primary care providers —DocStyles, 2018. *Am J Health Promot* 2021;35 (4):559–70. 10.1177/0890117120981371. [PubMed: 33356415]
- [14]. American Academy of Neurology. *Policy & Guidelines Epilepsy*, <http://www.aan.com/Guidelines/home/ByTopic?topicId=23> [accessed 12 November 2020].
- [15]. National Institute for Health and Clinical Excellence. *The Epilepsies: The Diagnosis and Management of the Epilepsies in Adults and Children in Primary and Secondary Care (update): Clinical Guideline 137*. London: Royal College of Physicians (UK) National Clinical Guideline Centre; 2012.
- [16]. Jackson MJ. Concise guidance: diagnosis and management of the epilepsies in adults. *Clin Med (Lond)* 2014;14(4):422–7. 10.7861/clinmedicine.14-4-422. [PubMed: 25099847]
- [17]. Rogers G The role of primary care in the management of epilepsy. In: Alarcon G, Valentin A, editors. *Introduction to Epilepsy*, Cambridge University Press, 2012, p.557–560.
- [18]. Labiner DM, Bagic AI, Herman ST, Fountain NB, Walczak TS, Gumnit RJ. Essential services, personnel, and facilities in specialized epilepsy centers—Revised 2010 guidelines. *Epilepsia* 2010;51:2322–2333. doi:10.1111/j.15281167.2010.02648.x. [PubMed: 20561026]
- [19]. Armstrong MJ, Gronseth GS. Approach to assessing and using clinical practice guidelines. *Neurol Clin Pract* 2018;8(1):58–61. 10.1212/CPJ.0000000000000417. [PubMed: 29517067]

- [20]. Armstrong MJ, Mullins CD. Value assessment at the point of care: incorporating patient values throughout care delivery and a draft taxonomy of patient values. *Value Health* 2017;20(2):292–5. 10.1016/j.jval.2016.11.008. [PubMed: 28237212]
- [21]. Vimalananda VG, Meterko M, Waring ME, et al. Tools to improve referrals from primary care to specialty care. *Am J Manag Care* 2019;25:e237–42. [PubMed: 31419100]
- [22]. Newman ED, Simonelli PF, Vezendy SM, Cedeno CM, Maeng DD. Impact of primary and specialty care integration via asynchronous communication. *Am J Manag Care* 2019;25:26–31. [PubMed: 30667608]
- [23]. Arora S, Kalishman S, Dion D, Som D, Thornton K, Bankhurst A, et al. Partnering urban academic medical centers and rural primary care clinicians to provide complex chronic disease care. *Health Aff.* 2011;30(6):1176–84. 10.1377/hlthaff.2011.0278.
- [24]. McPhillips AM, Schultz RJ, Nasuta M, Shafer PO. ECHO telementoring applied to managing students with seizures: the benefits for school nurses. *NASN Sch Nurs* 2021;36(2):104–9. 10.1177/1942602X20963720.
- [25]. McDonald SB, Privitera M, Kakacek J, Owens S, Shafer P, Kobau R. Developing epilepsy training capacity for primary care providers using the Project ECHO Telementoring model. *Epilepsy Behav* 2021;116:107789. 10.1016/j.yebeh.2021.107789.
- [26]. American Academy of Family Physicians (AAFP). AAFP Fellowship Directory, www.aafp.org/medical-education/directory/fellowship/search [accessed 9 October, 2020].
- [27]. Tan CH, Hungerford DW, Denny CH, McKnight-Eily LR. Screening for alcohol misuse: Practices among U.S. primary care providers, DocStyles 2016. *Am J Prev Med* 2018;54:173–180. [PubMed: 29241721]
- [28]. Quader ZS, Cogswell ME, Fang J, Coleman King SM, Merritt RK, Buchowski M. Changes in primary healthcare providers' attitudes and counseling behaviors related to dietary sodium reduction, DocStyles 2010 and 2015. *PLoS ONE* 2016;12(5):e0177693. 10.1371/journal.pone.0177693.
- [29]. Burns ER, Haddad YK, Parker EM. Primary care providers' discussion of fall prevention approaches with their older adult patients—DocStyles 2014. *Prev Med Rep* 2018;9:149–52. 10.1016/j.pmedr.2018.01.016. [PubMed: 29527468]
- [30]. Fang J, Ayala C, Loustalot F. Primary care providers' recommendations for hypertension prevention, DocStyles Survey, 2012. *J Prim Care Community Health* 2015;6(3):170–6. 10.1177/2150131915568997. [PubMed: 25653043]
- [31]. Smart NA, Dieberg G, Ladhani M, Titus T. Early referral to specialist nephrology services for preventing the progression to end-stage kidney disease In: Titus T, editor. *Cochrane Database Syst Rev.* 2014;18(6):CD007333. doi:10.1002/14651858.CD007333.pub2.
- [32]. Emdin CA, Hsiao AJ, Kiran A, Conrad N, Salimi-Khorshidi G, Woodward M, et al. Referral for specialist follow-up and its association with post-discharge mortality among patients with systolic heart failure (from the National Heart Failure Audit for England and Wales). *Am J Cardiol* 2017;119(3):440–4. 10.1016/j.amjcard.2016.10.021. [PubMed: 27884420]
- [33]. Hargreaves DS, Arora S, Viveiro C, Hale DR, Ward JL, Sherlaw-Johnson C, et al. Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study. *Lancet Child Adolesc Health* 2019;3(9):627–35. 10.1016/S2352-4642(19)30201-9. [PubMed: 31281027]
- [34]. Sveinsson O, Andersson T, Mattsson P, Carlsson S, Tomson T. Pharmacologic treatment and SUDEP risk: a nationwide, population-based, case-control study. *Neurology* 2020;95(18):e2509–18. 10.1212/WNL.0000000000010874. [PubMed: 32967928]
- [35]. Verducci C, Friedman D, Donner E, Devinsky O. Genetic generalized and focal epilepsy prevalence in the North American SUDEP registry. *Neurology* 2020;94(16):e1757–63. 10.1212/WNL.0000000000009295. [PubMed: 32217773]
- [36]. Arts DL, Voncken AG, Medlock S, van Weert A-HHC Reasons for intentional guideline non-adherence: a systematic review. *Int J Med Inform* 2016;89:55–62. 10.1016/j.ijmedinf.2016.02.009. [PubMed: 26980359]

- [37]. Murad MH. Clinical practice guidelines: a primer on development and dissemination. *Mayo Clin Proc* 2017;92(3):423–33. 10.1016/j.mayocp.2017.01.001. [PubMed: 28259229]
- [38]. Sapkota S, Kobau R, Croft JB, King VA, Thomas C, Zack MM. Prevalence and trends in cigarette smoking among adults with epilepsy—United States, 2019–2017. *MMWR Morb Mortal Wkly Rep* 2020;69:1792–6. [PubMed: 33237898]
- [39]. Zack M, Luncheon C. Adults with an epilepsy history, notably those 45–64 years old or at the lowest income levels more often report heart disease than adults without an epilepsy history. *Epilepsy Behav.* 2018;86:208–1201. 10.1016/j.yebeh.2018.05.021. [PubMed: 29908906]
- [40]. Wilson DA, Malek AM, Wagner JL, Wannamaker BB, Selassie AW. Mortality in people with epilepsy: a statewide retrospective cohort study. *Epilepsy Res.* 2016;122:7–14. 10.1016/j.eplepsyres.2016.01.008. [PubMed: 26900886]
- [41]. Lowerison MW, Josephson CB, Jetté N, Sajobi TT, Patten S, Williamson T, et al. Association of levels of specialized care with risk of premature mortality in patients with epilepsy. *JAMA Neurol* 2019;76(11):1352. 10.1001/jamaneurol.2019.2268. [PubMed: 31380987]

Table 1

Epilepsy and Seizure Disorder Questions on the 2018 DocStyles-A Survey, Porter Novelli.

Survey question	Response options
1. What percent of your patients have epilepsy or a seizure disorder?	_____% If none, please enter "0".
2. When a patient of yours develops seizures, what do you do?	<i>Select all that apply.</i> Diagnose Treat Review treatment guidelines Refer to a specialist None of these
3. When would you refer your patients with epilepsy or a seizure disorder to a neurologist?	<i>Select all that apply.</i> To determine/confirm the diagnosis To determine/confirm appropriate treatment Patient fails to respond to treatment Patient has a change in seizure activity Patient requests a referral to a neurologist None of these
4. Which of the following factors do you consider in deciding to refer your patients with epilepsy or a seizure disorder to a neurologist?	<i>Select all that apply.</i> Patient has insurance Patient lives near neurologist's office Prompt appointments available I can talk with the neurologist Neurologist returns patient to me for care Access to prompts or referral system None of these
5. What are the main barriers to referring your epilepsy/seizure disorder patients to a neurologist?	<i>Select all that apply.</i> I don't know where to refer them to My patients aren't interested Prompt appointments aren't available Patients' insurance doesn't cover it Patients lack transportation to get there None of these

Table 2

Provider actions for new-onset seizure patients, overall and by percentage of epilepsy caseload and provider type, Porter Novelli DocStyles-A Survey, 2018

No.	Overall (N = 1,284)		Epilepsy case load % 95% LCI, UCI*		Healthcare Provider Type % 95% LCI, UCI*				
	% (95% LCI-UCI)	1%-5% (n = 978)	6%-10% (n = 193)	11%+ (n=113)	Family practitioner (n = 422)	Internist (n = 432)	Pediatrician (n = 233)	Nurse practitioner (n = 197)	
Diagnose	45.2 39.8, 45.3	40.3 37.1, 43.5	48.7 41.4, 56.0	51.3 41.7, 60.9	37.9 33.2, 42.8	52.1 47.2, 56.9	48.5 41.9, 55.2	24.4 18.5, 31.0	
Treat	39.2 36.4, 42.0	33.8 30.8, 37.0	49.7 42.4, 57.1	67.3 57.7, 75.8	38.4 33.7, 43.3	53.7 48.8, 58.5	23.2 17.9, 29.2	27.9 21.7, 34.8	
Review treatment guidelines	29.1 26.6, 31.7	25.9 23.1, 28.8	35.2 28.5, 42.5	46.9 37.4, 56.6	28.2 23.9, 32.8	31.7 27.3, 36.4	25.3 19.8, 31.5	29.9 23.6, 36.9	
Refer to a specialist	90.0 88.2, 91.7	94.0 92.2, 95.4	81.9 75.6, 87.1	69.9 60.5, 78.2	91.0 87.8, 93.6	83.1 79.2, 86.6	97.9 95.0, 99.3	93.9 89.6, 96.9	
None of these	0.5 0.2, 1.2	0.4 0.1, 1.1	1.0 0.1, 3.7	0.9 0.0, 4.9	0.2 0.0, 1.4	0.5 0.0, 1.7	0.0 0.0, 1.3	2.0 0.5, 5.2	
Multiple responses									
Only refer	42.9 40.1, 45.7	48.4 45.1, 51.6	30.1 23.6, 37.1	17.7 11.1, 26.1	47.4 42.5, 52.3	30.8 26.4, 35.4	45.5 38.9, 52.2	56.9 49.6, 63.9	
Manage with guidelines & refer [‡]	15.4 13.4, 17.6	14.3 12.1, 16.7	17.6 12.5, 23.8	21.2 14.1, 30.0	14.7 11.4, 18.5	18.8 15.1, 22.8	12.4 8.4, 17.4	13.2 8.8, 18.8	
Manage without guidelines & refer [‡]	10.4 8.7, 12.2	10.1 8.3, 12.2	10.9 6.8, 16.2	11.5 6.2, 18.9	9.5 6.8, 12.7	15.7 12.4, 19.6	7.3 4.3, 11.5	4.1 1.7, 7.9	
Diagnose and refer	8.2 6.7, 9.9	8.8 7.0, 10.8	8.8 5.2, 13.2	1.8 0.2, 6.3	6.6 4.4, 9.5	6.5 4.3, 9.3	18.9 14.0, 24.6	2.5 0.8, 5.9	
Review guidelines and refer	4.6 3.5, 5.9	4.3 3.1, 5.8	4.7 2.1, 8.7	7.1 3.1, 13.5	4.7 2.9, 7.3	3.2 1.7, 5.4	3.0 1.2, 6.1	9.1 5.5, 14.1	

Notes. LCI = Lower confidence interval; UCI = Upper confidence interval.

[‡]Manage with guidelines & refer = Diagnose, treat, review epilepsy treatment guidelines, and refer.

[‡]Manage without guidelines & refer = Diagnose, treat, does not review epilepsy treatment guidelines, and refer.

Circumstances when a provider would refer a patient with epilepsy or seizure disorder to a neurologist – overall and by epilepsy caseload and provider type, Porter Novelli DocStyles-A Survey, 2018

Table 3

	Overall (N = 1,284)		Epilepsy case load % (95% LCI, UCI)*		Healthcare Provider Type % (95% LCI, UCI)*				
	N	% (95% LCI, UCI)	1%-5% (n = 978)	6%-10% (n = 193)	11%+ (n=113)	Family practitioner (n = 422)	Internist (n = 432)	Pediatrician (n = 233)	Nurse practitioner (n = 197)
To determine/ confirm the diagnosis	981	76.4 73.9, 78.8	80.2 77.5, 82.7	70.5 63.4, 76.9	54.0 44.3, 63.4	76.8 72.4, 80.8	69.9 65.3, 74.2	85.0 79.7, 89.4	79.7 73.3, 85.1
To determine/ confirm appropriate treatment	1072	82.3 81.3, 85.5	85.6 83.2, 87.8	79.8 73.4, 85.3	71.7 62.4, 79.8	85.1 81.3, 88.4	78.0 73.8, 81.9	90.6 86.0, 94.0	83.8 77.8, 88.7
Patient fails to respond to treatment	722	56.2 53.4, 59.0	54.8 51.6, 58.0	61.7 54.4, 68.6	59.3 49.6, 68.5	58.5 53.6, 63.3	62.7 57.9, 67.4	48.5 41.9, 55.2	46.2 39.0, 53.5
Patient has a change in seizure activity	818	63.7 61.0, 66.4	65.3 62.2, 68.4	63.2 55.9, 70.1	50.4 40.8, 60.0	68.7 64.0, 73.2	62.3 57.5, 66.9	62.2 55.6, 68.5	57.9 50.6, 64.9
Patient requests a referral to a neurologist	838	65.3 62.5, 67.9	67.9 64.8, 70.9	61.1 53.8, 68.1	49.6 40.0, 59.2	66.4 61.6, 70.9	65.3 60.5, 69.8	66.5 60.0, 72.6	61.4 54.2, 68.3
None of these	12	0.9 0.4, 1.7	0.6 0.2, 1.4	1.0 0.1, 3.7	3.5 0.9, 8.9	0.2 0.0, 1.4	0.9 0.2, 2.4	0.0 0.0, 1.3	3.6 1.4, 7.2
Multiple responses									
Diagnose, treat, fail to respond, change seizure activity, refer	452	35.2 32.5, 37.9	38.3 35.2, 41.5	29.5 23.1, 36.6	17.7 11.1, 26.1	37.7 33.0, 42.5	33.8 29.3, 38.5	36.1 29.8, 42.6	32.0 25.5, 39.0
Diagnose, treat	135	10.5 8.8, 12.4	11.5 9.5, 13.7	6.7 3.6, 11.3	8.8 4.3, 15.7	8.1 5.6, 11.1	8.8 6.2, 11.9	15.9 11.4, 21.3	13.2 8.8, 18.8
Diagnose, treat, change seizure activity, refer	117	9.1 7.5, 10.9	10.0 8.2, 12.1	7.3 4.0, 11.9	4.4 1.4, 10.1	10.4 7.6, 13.8	5.6 3.5, 8.2	12.0 8.1, 16.9	10.7 6.7, 15.9
Diagnose, treat, refer	91	7.1 5.7, 8.7	7.1 5.5, 8.9	7.8 4.4, 12.5	6.2 2.5, 12.4	5.5 3.4, 8.1	6.3 4.1, 9.0	9.0 5.6, 13.5	10.2 6.3, 15.3
Treat	75	5.8 4.6, 7.3	5.4 4.0, 7.1	6.2 3.2, 10.7	8.8 4.3, 15.7	6.2 4.0, 8.9	5.6 3.5, 8.2	6.9 3.9, 11.0	4.6 2.1, 8.5

Notes. LCI = Lower confidence interval; UCI = Upper confidence interval.

* Manage with guidelines & refer = Diagnose, treat, review epilepsy treatment guidelines, and refer.

‡ Manage without guidelines & refer = Diagnose, treat, does not review epilepsy treatment guidelines, and refer.

Table 4

Enabling factors important for epilepsy or seizure disorder patient referrals to neurologists – overall and by epilepsy caseload and healthcare provider type, Porter Novelli DocStyles-A Survey, 2018.

	Overall (N = 1,284)		Epilepsy case load		Healthcare Provider Type					
	N	% (95% LCI, UCI)	% (95% LCI, UCI)*	1%-5%	6%-10%	11%+	Family practitioner	Internist	Pediatrician	Nurse practitioner
			(n = 978)	(n = 193)	(n = 113)	(n = 422)	(n = 432)	(n = 233)	(n = 197)	
Prompt appointment available	527	41.0 38.3, 43.8	39.7 36.5, 42.9	49.2 41.9, 56.5	38.9 29.9, 48.6	42.4 37.6, 47.3	39.8 35.1, 44.7	39.1 32.7, 45.7	43.1 36.1, 50.4	
Access to prompts or referral system	506	39.4 36.7, 42.2	38.4 35.3, 41.6	43.5 36.4, 50.9	40.7 31.5, 50.4	36.5 31.8, 41.3	38.9 34.2, 43.7	40.3 33.9, 47.0	45.7 38.5, 53.0	
I can talk with the neurologist	470	36.6 33.9, 39.4	35.6 32.5, 38.7	40.9 33.9, 48.3	38.1 29.0, 47.7	33.4 28.9, 38.2	44.2 39.4, 49.1	34.8 28.6, 41.3	28.9 22.7, 35.9	
Patient has insurance	452	35.2 32.5, 37.9	34.6 31.5, 37.7	39.9 32.9, 47.2	32.7 24.2, 42.3	39.8 35.1, 44.7	34.3 29.7, 39.0	24.0 18.6, 30.1	40.6 33.6, 47.9	
Neurologist returns patient to me for care	399	31.1 28.5, 33.7	30.3 27.3, 33.3	34.2 27.5, 41.4	32.7 24.2, 42.3	37.4 32.8, 42.3	28.5 24.2, 33.0	26.2 20.6, 32.4	28.9 22.7, 35.9	
Patient lives near neurologist's office	186	14.5 12.6, 16.6	12.1 10.0, 14.3	18.1 12.9, 24.4	29.2 21.0, 38.6	16.4 12.9, 20.3	16.4 13.0, 20.3	10.3 6.7, 15.0	11.2 7.1, 16.5	
None of these	216	16.8 14.8, 19.0	18.5 16.1, 21.1	11.4 7.2, 16.8	11.5 6.2, 18.9	14.4 11.2, 18.2	15.0 11.8, 18.8	25.3 19.8, 31.5	15.7 10.9, 21.6	
Multiple responses										
Only access to prompts or referral system	99	7.7 6.3, 9.4	7.9 6.2, 9.8	7.3 4.0, 11.9	7.1 3.1, 13.5	5.7 3.6, 8.4	7.6 5.3, 10.6	9.4 6.0, 14.0	10.2 6.3, 15.3	
Only patient has insurance	67	5.2 4.0, 6.6	5.8 4.4, 7.5	3.1 1.1, 6.7	3.5 0.9, 8.9	7.8 5.4, 10.9	4.6 2.8, 7.1	3.0 1.2, 6.1	3.6 1.4, 7.2	
Only prompt appointment available	64	5.0 3.8, 6.4	4.4 3.1, 5.9	7.3 4.0, 11.9	6.2 2.4, 12.5	4.5 2.7, 7.0	5.3 3.4, 7.9	5.2 2.6, 8.9	5.1 2.4, 9.2	
Access to prompts, prompt appointment available	42	3.3 2.3, 4.4	3.6 2.5, 5.0	3.6 1.4, 7.4	0.0 0.0, 2.7	2.4 1.1, 4.4	2.3 1.1, 4.3	4.7 2.7, 8.3	5.6 2.8, 9.8	

Notes. LCI = Lower confidence interval; UCI = Upper confidence interval.

* Manage with guidelines & refer = Diagnose, treat, review epilepsy treatment guidelines, and refer.

Table 5

Barriers against referrals for epilepsy or seizure disorder patients to neurologists – overall and by epilepsy caseload and healthcare provider type, Porter Novelli DocStyles-A Survey, 2018

	Overall (N = 1,284)	Epilepsy case load					Healthcare Provider Type				
		N	% (95% LCI, UCI)	1%-5% (n = 978)	6%-10% (n = 193)	11%+ (n=113)	Family practitioner (n = 422)	Internist (n = 432)	Pediatrician (n = 233)	Nurse practitioner (n = 197)	
Prompt appointments aren't available	690	53.7 50.9, 56.5	52.5 49.2, 55.7	58.0 50.7, 65.1	57.5 47.8, 66.8	54.3 49.3, 59.1	50.7 45.8, 55.6	55.8 49.1, 62.3	56.9 49.6, 63.9		
Patient's insurance doesn't cover it	515	40.1 37.4, 42.9	38.1 35.0, 41.3	47.2 39.9, 54.5	45.1 35.7, 54.8	45.0 40.2, 50.0	38.2 33.5, 43.0	30.9 25.0, 37.3	44.7 37.6, 52.0		
Patient lacks transportation to get there	331	25.8 23.4, 28.3	23.7 21.0, 26.6	35.2 28.5, 42.5	27.4 19.4, 36.7	29.4 25.0, 34.0	23.1 19.2, 27.5	17.2 12.5, 22.7	34.0 27.4, 41.1		
My patients aren't interested	211	16.4 14.4, 18.6	14.0 11.8, 16.4	19.2 13.8, 25.5	32.7 24.2, 42.3	18.0 14.4, 22.1	24.1 20.1, 28.4	4.3 2.0, 7.8	10.7 6.7, 15.9		
I don't know where to refer them	47	3.7 2.7, 4.9	3.7 2.5, 5.1	3.6 1.4, 7.4	3.5 0.9, 8.9	3.1 1.6, 5.3	5.3 3.4, 7.9	2.6 0.9, 5.6	2.5 0.8, 5.9		
None of these	280	21.8 19.5, 24.2	24.8 22.1, 27.7	11.4 7.2, 16.8	13.3 7.6, 21.0	16.6 13.1, 20.5	23.4 19.4, 27.7	29.6 23.8, 36.0	20.3 14.9, 26.7		
Multiple responses											
Only no prompt appointments available	249	19.4 17.2, 21.7	20.0 17.5, 22.7	16.1 11.1, 22.1	19.5 12.6, 28.0	18.5 14.8, 22.6	16.2 12.8, 20.1	28.3 22.6, 34.6	17.8 12.6, 23.9		
No prompt appointments and no insurance.	157	12.2 10.4, 14.2	12.2 10.1, 14.4	13.0 8.5, 18.6	11.5 6.2, 18.9	13.3 10.1, 16.9	9.3 6.6, 12.4	14.2 9.9, 19.4	14.2 9.6, 19.9		
Only no patient insurance.	93	7.2 5.8, 8.8	7.4 5.8, 9.2	9.3 5.6, 14.4	2.7 0.5, 7.6	8.8 6.2, 11.9	7.2 4.9, 10.1	6.0 3.3, 9.9	5.6 2.8, 9.8		
No prompt appointments, No insurance, and no transport.	92	7.2 5.8, 8.8	7.1 5.5, 8.9	8.3 4.8, 13.2	6.2 2.5, 12.4	8.8 6.2, 11.9	6.3 4.1, 9.0	3.9 1.7, 7.3	9.6 5.9, 14.7		
No prompt appointments andno transport	71	5.5 4.3, 7.0	5.4 4.0, 7.1	8.3 4.8, 13.2	1.8 0.2, 6.3	5.7 3.6, 8.4	3.7 2.1, 6.0	6.0 3.3, 9.9	8.6 5.1, 13.5		

Notes. LCI = Lower confidence interval; UCI = Upper confidence interval.