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Sharath Kumar Anand

Mohamed Macki

Lauren G. Culver

Vibhangini S. Wasade

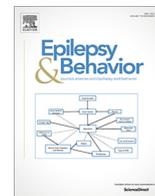
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Authors

Sharath Kumar Anand, Mohamed Macki, Lauren G. Culver, Vibhangini S. Wasade, Samantha Hendren, and Jason M. Schwalb



Editorial

Patient navigation in epilepsy care

Sharath Kumar Anand^{a,*}, Mohamed Macki^b, Lauren G. Culver^a, Vibhangini S. Wasade^{c,d}, Samantha Hendren^e, Jason M. Schwalb^{b,f}

^a Wayne State University School of Medicine, 540 E Canfield St., Detroit, MI, USA

^b Department of Neurosurgery, Henry Ford Hospital, 2799 W Grand Blvd, Detroit, MI, USA

^c Department of Neurology, Henry Ford Hospital, 2799 W Grand Blvd, Detroit, MI, USA

^d Department of Neurology, Wayne State University School of Medicine, 540 E Canfield St., Detroit, MI, USA

^e Division of Colorectal Surgery, Department of Surgery, University of Michigan, 1500 E Medical Center Dr., Ann Arbor, MI, USA

^f Center for Health Policy and Health Services Research, Henry Ford Health System, 2799 W Grand Blvd, Detroit MI 48202, USA



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ABSTRACT

The concept of patient navigation was first introduced in 1989 by the American Cancer Society and was first implemented in 1990 by Dr. Harold Freeman in Harlem, NY. The role of a patient navigator (PN) is to coordinate care between the care team, the patient, and their family while also providing social support. In the last 30 years, patient navigation in oncological care has expanded internationally and has been shown to significantly improve patient care experience, especially in the United States cancer care system. Like oncology care, patients who require epilepsy care face socioeconomic and healthcare system barriers and are at significant risk of morbidity and mortality if their care needs are not met. Although shortcomings in epilepsy care are longstanding, the COVID-19 pandemic has exacerbated these issues as both patients and providers have reported significant delays in care secondary to the pandemic. Prior to the pandemic, preliminary studies had shown the potential efficacy of patient navigation in improving epilepsy care. Considering the evidence that such programs are helpful for severely disadvantaged cancer patients and in enhancing epilepsy care, we believe that professional societies should support and encourage PN programs for coordinated and comprehensive care for patients with epilepsy.

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1. Patient navigation in oncological care

The concept of patient navigation was first introduced in 1989 following the American Cancer Society "National Hearings on Cancer in the Poor." After hearing testimony from low-income United States (US) citizens of various races and ethnicities diagnosed with cancer, the committee concluded that these patients face greater barriers in seeking and obtaining cancer care than their more privileged counterparts. Further, these barriers often actively prevented them from obtaining cancer care and led to poor outcomes and greater suffering [1]. After confronting late-stage breast cancers in his low-income and minority patients in Harlem, NY, Dr. Harold Freeman initiated the first patient navigation program in the US in 1990. This program focused on ensuring the continuity of care from diagnosis to treatment and beyond for patients

with cancer, with a patient navigator (PN) from the community tasked with guiding patients and their families through social, economic, financial, cultural, bureaucratic, and psychological barriers that often hindered their access to healthcare services [1,2].

In the last 30 years, patient navigation programs to assist cancer patients have been implemented in the United States, Australia, Canada, Sweden, Denmark, and Brazil. In the modern US cancer care system, there is evidence that PNs improve the care experience for patients and their families [3–5]. While evidence proving the benefits of PNs in improving cancer outcomes is mixed, the impact on cancer care quality is greatest when they are targeted to populations with severe socioeconomic disparities and for diseases where there is poor adherence to guidelines [6]. This describes perfectly the situation of epilepsy care in the United States. Here, we make the argument that there is an urgent need to improve epilepsy care, due to the socioeconomic and healthcare system barriers to care faced by the patients, as well as the well-documented risks faced by patients who do not receive high-quality care. The PN is one of the few interventions that might change this situation and improve outcomes.

* Corresponding author at: School of Medicine, Wayne State University, 540 E Canfield St, Detroit, MI 48201, USA.

E-mail address: asharath@med.wayne.edu (S.K. Anand).

2. Patient navigation in epilepsy care

The severe socioeconomic disadvantages of patients with medically refractory epilepsy make this patient population an attractive target for placement of PNs. Studies have found non-white and socioeconomically disadvantaged individuals are disproportionately affected by epilepsy, and yet they are less likely to receive anti-seizure medications, less likely to undergo surgical treatment, and less likely to receive specialized care [7–13]. Nathan et al. eloquently attributes these disparities to 6 key factors using the acronym FACETS – 1) Fear of treatment, 2) Access to care, 3) Communication barriers, 4) Education, 5) Trust between patient and physician, and 6) Social support [9]. They also propose possible interventions such as “patient education and empowerment,” social workers, patient-provider racial concordance, community engagement, and strict adherence to post-procedure follow-up with a social worker or community contact to target and mitigate these disparities [9]. Similarly, Pieters et al. reported testimonies of epilepsy patient caretakers of the trials and tribulations of navigating the road to epilepsy surgery. These caretakers often found the journey to epilepsy surgery to be arduous, lonely, and distressing, especially considering the complexity of epilepsy and the need to make urgent decisions in limited time periods. Like Nathan et al., Pieters et al. also proposed mechanisms to alleviate these struggles, specifically, social support for patients and caretakers, shared decision making between providers, patients, and caretakers, and the “need for one professional who champions and navigates care” [14]. Without explicitly using the terms “patient navigator” or “nurse navigator,” Nathan et al. and Pieters et al. advocate for an individual who can educate and empower patients, provide post-procedural follow-up, provide social support, facilitate shared decision making, and serve as the point of contact to champion and navigate care.

Despite the lack of national guidelines for PNs in epilepsy care, a few researchers have sought to implement such programs in their own practice. Drees et al. from the University of Colorado studied the effects of certain interventions, including increasing the number of patient care conferences, enabling faster access to intracarotid amobarbital testing, adding a dedicated epilepsy surgery clinic, and hiring a nurse navigator (i.e., PN) to coordinate presurgical evaluation of epilepsy patients. They found that these interventions led to a decrease in time to epilepsy surgery by almost 100 days and almost tripled the rate of annual epilepsy surgeries. Although they were unable to identify the effect of each individual intervention, they found that the addition of a nurse navigator, specifically, added extra benefit, especially in significantly reducing the time to surgery as compared to the baseline group [15].

The effects of the interventions introduced by Drees et al. are especially significant when considering the mortality of untreated or undertreated epilepsy. Studies have found that overall mortality in patients with epilepsy is 1.6–3.0 times greater when compared to the general population. Those mortality numbers increase to 2.2 to 6.5-fold greater in patients with epilepsy of known etiology when compared to the general population [16]. The most common epilepsy-related cause of death is Sudden Unexplained Death in Epilepsy (SUDEP). Sudden Unexplained Death in Epilepsy affects between 1.5 and 5.9 per 1000 person-years in patients with refractory epilepsy and 6.3–9.3 among those who are candidates for epilepsy surgery [17]. Sudden Unexplained Death in Epilepsy risk is increased with lack of seizure freedom, nocturnal seizures, and as few as one generalized tonic-clonic seizure a year [18]. The risks of SUDEP, as well as mortality from seizure-related trauma, drowning and status epilepticus, can be significantly reduced with epilepsy surgery: in a 35-year-old patient, an average anterior temporal lobectomy adds 5 years of life and 7.5 quality-adjusted

life years (QALYs). However, despite the demonstrable efficacy of epilepsy surgery, patients, on average, wait between 17 and 23 years from seizure onset to surgery [19–21]. Even then epilepsy surgery remains underutilized, with many patients never receiving the benefits of surgery [22]. Efforts to decrease the time to surgery, such as those interventions introduced by Drees et al., would not only decrease the amount of time patients are at risk for mortality and SUDEP, but also potentially increase survival, seizure-free survival, and quality of life.

3. The COVID-19 pandemic and epilepsy care

While these shortcomings in epilepsy care are longstanding, the COVID-19 pandemic has exacerbated these gaps, hindering both diagnosis and access to treatment. Although efforts have been made to accommodate epilepsy concerns with telemedicine, these efforts are limited by many factors. Patients of lower socioeconomic status may not have access to telemedicine and struggle to maintain reliable lines of communication [23]. Furthermore, despite the serious risks of poorly controlled epilepsy, many neurologists and specialty nurses from Comprehensive Epilepsy Centers were redeployed to acute care COVID units, and may be again [23]. For example, during the height of the pandemic, we had a patient whose generalized convulsive seizure frequency increased from 1 every 3–4 months to 1 a week, associated with end of life of his vagus nerve stimulator internal pulse generator. There was a delay in delivery of prompt care for this patient which may have been averted, had there been adequate resources allocated to help him navigate the system and receive proper, timely care for his intractable epilepsy. In one survey of pediatric epilepsy clinicians, 97.8% reported a change in practice due to the pandemic, described as either a reduction of non-life-threatening cases or complete suspension of epilepsy surgery [24]. These acute interruptions in inpatient epilepsy care and outpatient follow-up not only lead to increased risk of patient attrition now, but also after the pandemic, when the backlog generated by pandemic leads to further delays in time-critical care. A PN, whose job it is to ensure appropriate, triaged follow-up and maintain those lines of communication with the patient, could help mitigate patient attrition rates from this pandemic.

Similarly to other problems in America, the COVID-19 pandemic has led to an acute exacerbation of the chronic problems affecting epilepsy care. Those communities affected most by epilepsy are the least likely to receive appropriate care and patients often wait years before receiving surgery, placing them at increased risk of morbidity and mortality. Physicians and healthcare workers have the responsibility to advocate and effect changes in care. Starting in 2015, the American College of Surgeons (ACoS) Commission on Cancer required a “patient navigation process” that is “established to address healthcare disparities and barriers to care for patients” as part of certification. Epilepsy advocates should demand the same.

4. Conclusion

Considering the evidence of such programs for severely disadvantaged patients with cancer and preliminary evidence in enhancing epilepsy care, we believe that professional societies should support and encourage patient navigation programs for coordinated and comprehensive care for epilepsy patients. Such programs are supported by the International League Against Epilepsy [25]. We propose that the National Association of Epilepsy Centers (NAEC), American Academy of Neurologists (AAN), American Epilepsy Society (AES), and Epilepsy Foundations include rec-

ommendations for patient navigation programs in their own recognition of Comprehensive Epilepsy Centers and in the requirements for accreditation process.

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Declaration of competing interests

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