

Epilepsy through the eyes of the media: A paradox of positive reporting and challenges of access to advanced neurotechnology

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ABSTRACT

Objective: Media coverage of disorders and medical advancements can impact public perception regarding the riskiness, effectiveness, and accessibility of treatment options. We studied that coverage for epilepsy with a focus on surgical interventions and emerging neurotechnologies.

Methods: Epilepsy-related English language articles published through 2019 were retrieved from online International news media with a circulation of 80,000 or above. We used directed content analysis of news articles to code content into a priori categories both to identify salient themes and to characterize their valence.

Results: One hundred forty-six unique articles matched our search terms. Overall, there was a steady increase in epilepsy reporting over time, with a majority of articles published with a positive tone. Neuromodulation was the focus of over 50% of all the articles in the time points analyzed. Vagus nerve stimulation (VNS) and deep-brain stimulation (DBS) were discussed more prominently than other types of neurotechnological interventions; VNS was the neurotechnological focus in 39% of the pediatric articles; resective surgery was the focus in 34% of adult articles. Access, support, and epilepsy literacy were the central themes in the context of ethical, legal, and social issues.

Significance: News media can influence the trust that the public places in science and medicine, and by extension, influences health policy. As innovations in neurotechnology for epilepsy emerge, understanding of individual and societal values is essential to their beneficial evolution and translation to care.

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1. Introduction

In 2016, epilepsy was estimated to affect approximately 45 million people globally and accounted for over 13 million disability-adjusted life years [1]. Despite the development of antiepileptic drugs, at least 30% of patients with epilepsy do not achieve adequate seizure control with pharmacological therapy [1]. The challenges that epilepsy presents in daily life may prompt patients and their families to explore alternative interventions in an attempt to alleviate the condition. Indeed, the development of surgical and novel neurotechnological approaches for

treating epilepsy is a rapidly expanding field, with its crude beginnings dating back to Ancient Greece and before.

Once attributed to supernatural causes, epilepsy was treated with trepanation in the Hippocratic Corpus, and it was not until the second half of the 19th century that the modern field of epileptology emerged [2]. Since the late 1990s, in addition to the longer standing practices of resective surgery in epilepsy, technologies intended to modulate the brain such as vagus nerve stimulation (VNS) and responsive neurostimulation (RNS) have become clinically available [3,4]. The 20th century also saw the advent of stereotactic radiosurgery such as Gamma Knife to be used in the treatment of epilepsy as well as other conditions [5].

Media coverage of epilepsy and new medical technologies can have a substantial impact on public attitudes toward the disorder and the riskiness, efficacy and accessibility of different treatment options. Patients and their families may turn to traditional news and social media as they seek information to make decisions about care [6,7]. In this light, we set out to explore the nature of press media coverage of

Abbreviations: VNS, Vagus nerve stimulation; DBS, Deep-brain stimulation; TNS, Trigeminal nerve stimulation; RNS, Responsive nerve stimulation; RE, Resective surgery; GK/SRS, Gamma knife/stereotactic radiosurgery; LA, Laser ablation; M/D, Monitoring and diagnostic technology; RES, Research and prototypes; RAS, Robot assisted surgery; PH, Pharmacological treatments; OT, Other therapies.

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epilepsy, with a particular interest in emerging innovations involving neurotechnology.

2. Methods

2.1. Sample

Major international newspapers with a circulation of 80,000 or greater that publish in English were identified by cross-referencing the most up-to-date information from the International Federation of Audit Bureaux of Certification, News Media Canada, Alliance for Audited Media, NewsMedia Works, and Enhanced Medic Metrics Australia. Using the Factiva database and search terms related to epilepsy/seizures and neurotechnology/ablative techniques, we compiled full-length articles from the selected newspapers (Table 1). Age group terms were included for an initial targeted search then excluded for breadth. The search returns were manually curated to exclude duplicate articles or articles that did not have epilepsy as a main concern.

2.2. Procedure

All data were made software-ready for management in NVivo (QSR-11) and qualitative analysis. The directed content analysis was carried out by two members of the research team (V.M. and M.A.) in two stages. First, a codebook was built during initial coding to elucidate subcategories corresponding to four a priori themes drawing upon the work of Cabrera et al. [8] on media coverage of psychiatric neurosurgery. Through the iterative coding process, the a priori themes separately relating to ethical, legal, and social issues (ELSI) were merged. The final groupings for thematic analysis were as follows: 1) science and technology, 2) patient considerations, and 3) ELSI. The two coders independently coded 10% of the articles in the sample. The unweighted kappa coefficient was calculated in NVivo and surpassed the desired threshold of 0.8, suggesting high coding concordance.

Using a coding strategy that allowed for the attribution of more than one code per category per article, the coding team noted the interventions of focus, tone (positive, negative, balanced, or neutral), patient age group (pediatric, adult, both, or not applicable). Articles were coded as having a positive tone if the message was optimistic or hopeful overall. For example, “*He felt he had run out of options, but after the treatment, his life has changed.*” Articles making comparisons between risk versus benefit, or pro versus con assessments were coded as balanced. Articles that made pronounced critical statements were coded as having a negative tone. For example, “*The surgery rendered her unable to*

continue her studies and live a normal life; it might have relieved her seizures, but at a great cost.” Finally, articles were coded as having a neutral tone when no valence could be identified.

When coding for age group, articles were coded as pediatric if they presented cases of patients 19 years old or younger, adult if presenting a case of a patient older than 19 years, both if articles presented cases regarding adult and pediatric patients, and not applicable if an article did not present a patient case. If an article contained information about the trajectory of treatment or disease of a patient from childhood to adulthood, it was categorized as either pediatric or adult depending on whether it contained a substantial content quantified by the coverage tool in NVivo.

Interventions were coded as follows: resective surgery (RE), Gamma Knife/Stereotactic radiosurgery (GK/SRS), laser ablation (LA), monitoring and diagnostic technology (M/D), deep-brain stimulation (DBS), vagus nerve stimulation (VNS), trigeminal nerve stimulation (TNS), and responsive neurostimulation (RNS). During analysis, RE, GK/SRS, and LA were combined to study data pertaining to ablative technologies as a whole. We coded for unspecified neurotechnology when neuromodulation was described but the exact device was not described, and research and prototypes (RES) for interventions that are not currently clinically available or are in clinical trials. We also coded for robot assisted surgery (RAS); pharmacological treatments (PH); other therapies (OT), such as herbal treatments; and other alternative interventions, such as relaxation, when the discussion prominently described the combination with neurotechnology.

For final analysis, we grouped articles into three time periods: before 2000, 2000–2009, and 2010–2019.

3. Results

A total of 146 articles published in news media from 5 countries ($n = 10$, Australia; $n = 12$, Canada; $n = 26$, India; $n = 51$, UK; $n = 47$, USA) met inclusion criteria.

3.1. Quantitative findings

3.1.1. Coverage of interventions over time

Articles published in the years prior to 2000 were limited compared to later periods, but coverage of epilepsy treatment overall rose steadily by decade since the earliest paper published in 1985 ($n = 18$ before 2000; $n = 53$, 2000–2009; $n = 75$, 2010–2019).

Over half of all the articles in each time period had a neuromodulation therapy as a focus point; ablative surgery was consistently the second most covered topic (22% before 2000; 34% in 2000–2009; 20% in 2010–2019) (Fig. 1); VNS was the dominant coverage point both before 2000 and in 2000–2009 (50%), but the category became more evenly split with other neurotechnologies in 2010–2019 (Fig. 2); DBS was a focus of 23% of articles during this latter period. Coverage of RES, which includes proposed therapies, such as wireless artifact-free neuromodulation device (WAND) and optogenetics, emerged in 2010–2019.

Across the 5 countries from which relevant media was retrieved, neuromodulation therapy was a focus point within each set (90% in Australia, $n = 10$; 69% in India, $n = 26$; 61% in the UK, $n = 51$; 68% in the USA, $n = 47$). In Canada, resective surgery (50%, $n = 12$) and neuromodulation (25%) dominated coverage.

3.1.2. Tone

Across time, most articles ($\geq 50\%$), regardless of therapy of focus, were positive (Fig. 3). There was limited data from the period prior to 2000s; however, of the ten articles published regarding neuromodulation, seven were positive, two were neutral, and one was balanced. Tone was similarly positive across neurotechnology groups (Fig. 4).

Table 1
Full search terms inputted to Factiva.

Search category	Factiva search terms
Epilepsy	(Epilepsy OR seizures OR Epilep* OR epileptic) AND
Age group	(pediatric OR paediatric OR child* OR adolescent or teenage* OR infant OR toddler OR kid*) AND
Neuromodulation	(neurotechnology OR neuromodulation OR neurostimulation OR Deep brain stimulation OR electrode implant OR brain implant OR brain pacemaker OR Vagus nerve stimulation OR nerve stimulation OR
Ablation (historical, contemporary)	Laser interstitial surgery OR laser interstitial thermal therapy OR (laser w/3 surgery) OR stereotactic laser surgery (stereotactic w/3 surgery) OR focused ultrasound OR craniotomy OR focal resection OR ablative neurosurgery OR ablative surgery OR radiosurgery OR amygdalectomy OR capsulotomy OR cingulotomy OR cyberknife OR gamma knife OR leucotomy OR lobotomy OR optogenetics OR psychiatric neurosurgery OR psychosurgery OR radiosurgery OR StereoEEG OR intracortical monitoring OR grid monitoring)

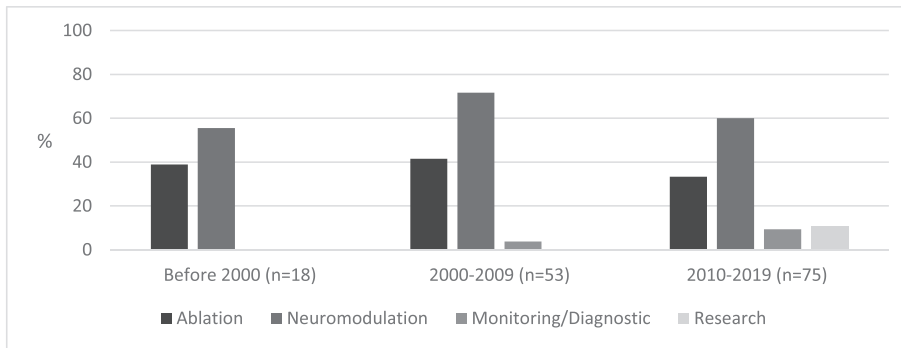


Fig. 1. Type of intervention/neurotechnology covered across time.

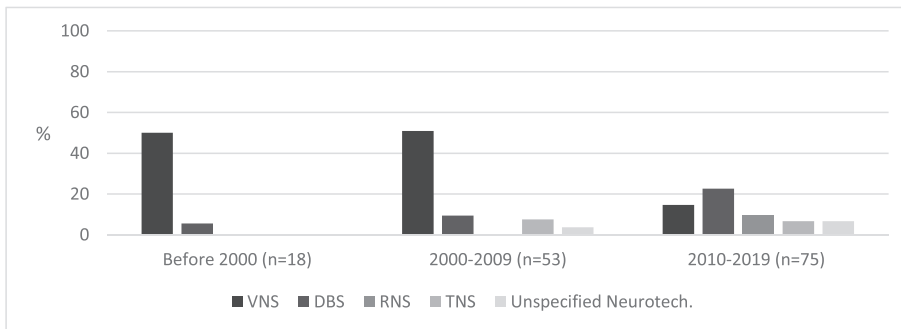


Fig. 2. Coverage of neuromodulation across time.

3.1.3. Therapy coverage for adult versus pediatric cases

The dominant point of focus in articles about children (39%) was VNS. Coverage of resective surgery dominated the adult articles (34%) (Fig. 5). Other therapies of interest undifferentially mapped onto articles about the two populations.

3.1.4. Ethical, legal, and social issues

We found 137 themes pertaining to ELSI across the articles analyzed. Access, support, and epilepsy literacy were the foremost ELSI issues discussed in the newspaper media overall, by type of interventions (Fig. 6), and by population (Fig. 7).

3.2. Interpretive analysis

3.2.1. Before 2000

Prior to 2000, news media mainly covered traditional resective surgeries but neuromodulation and stereotactic radiosurgery quickly began to

gain traction as these new technologies became available in the late 1990s. *The Washington Post* reported on a left hemispherectomy for a 4-year-old patient (1985, “Maranda Story To Stop the seizures that were destroying her life, doctor’s removed the left half of her brain”) and just over ten years thereafter, *The Times* reported on VNS in the treatment of an 8-year-old’s epilepsy that restored her speech (1996, “Pioneer surgery restores speech to epilepsy child”). There was a stark contrast between the established, lengthy, surgical techniques of the time and the less invasive and quick neurotechnologies that were emerging.

3.2.2. 2000–2009

Beginning in the year 2000, there was an increase in overall media coverage that included a greater variety of modern therapies and especially featured success stories:

Since having the [VNS] implant three years ago, Natalie’s “dizzy dos” have reduced by 80 per cent. On a good week she might only fit twice. Four months after the op, she re-sat the A-Levels she failed

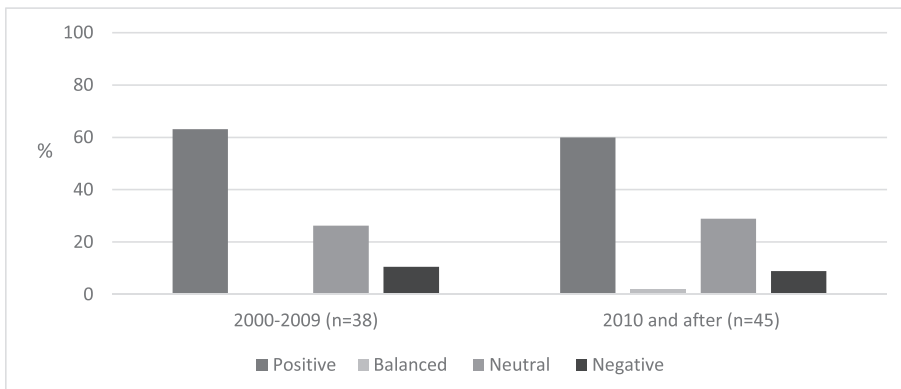


Fig. 3. Tone over time.

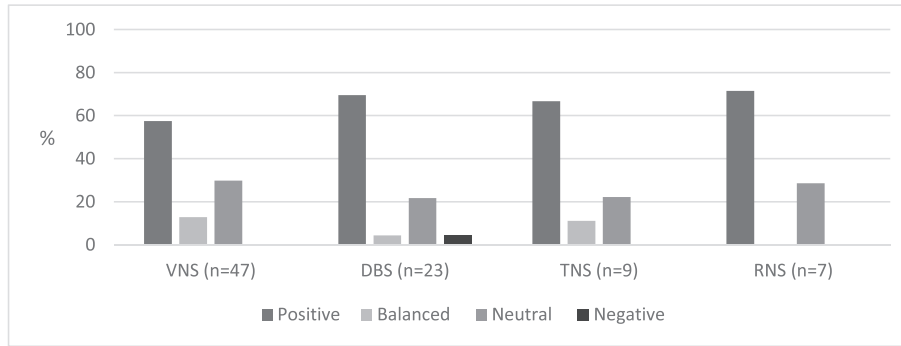


Fig. 4. Tone of news articles for neurotechnologies.

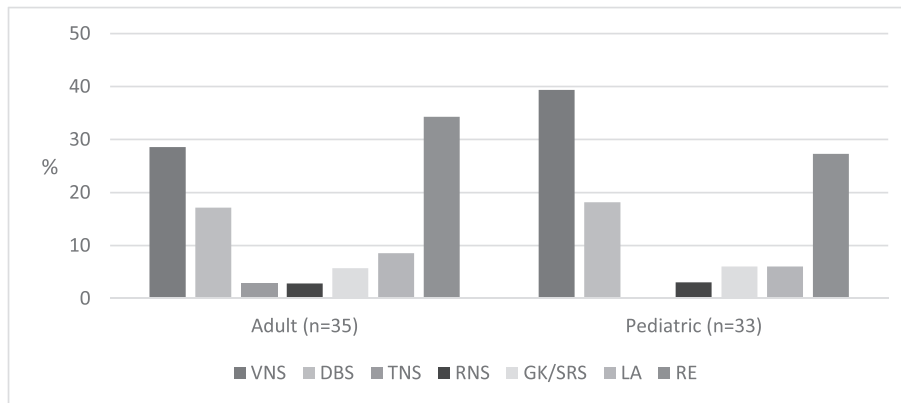


Fig. 5. Therapies of focus for articles about children and adults.

the year before - and passed with flying colours. (*Daily Mirror*, 2005, “Your Life: Health: An old woman beat me for being a drunk... in fact I was having a SEIZURE”)

Before 2000 and continuing on into the next decade, a coverage point was access to neuromodulatory treatment and the reluctance of insurance providers to cover the cost of treatments.

Doctors laud [VNS] effectiveness and say it is becoming a standard treatment for the disease...The device has a price tag of \$11,460; the surgery to implant it can boost the cost to \$15,000 or \$18,000. In Florida, Medicaid reimburses only about \$1,000 to \$2,000 of that, in contrast to 44 other states that pay enough of the bill to make it worthwhile for hospitals to do the surgery, said Max Gill, an agent for Cyberonics, the company that makes the equipment. (*Tampa*

Bay Times, 2000, “TREATING EPILEPSY // State won’t cover seizure treatment”)

Within an overall positive reporting landscape, the 2000–2009 decade defined a shift from cautious hopefulness to optimism about neurotechnology. Patient success stories, quotes from physicians applauding the devices, and marketing of the attractive qualities of the therapies – less serious side effects, shorter operations – became prominent talking points.

3.2.3. 2010–2019

In this third period of analysis, we observed that while coverage remained positive for neurotechnologies, qualitatively a new found balance between excitement and realistic outcomes emerged:

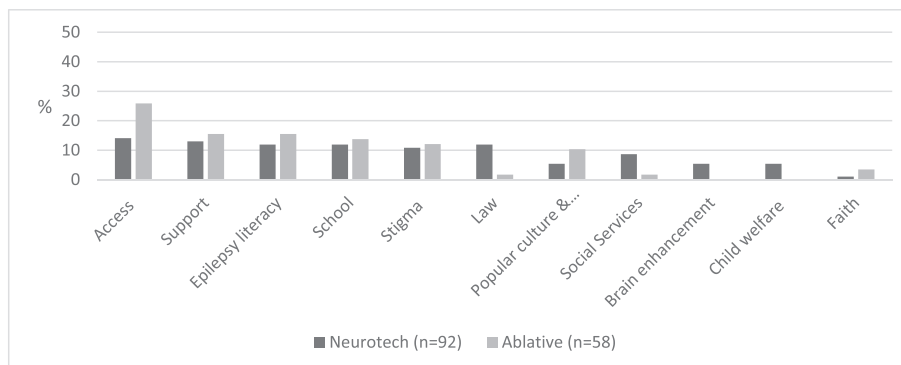


Fig. 6. Relative percent frequency of ELSI themes by type of therapy.

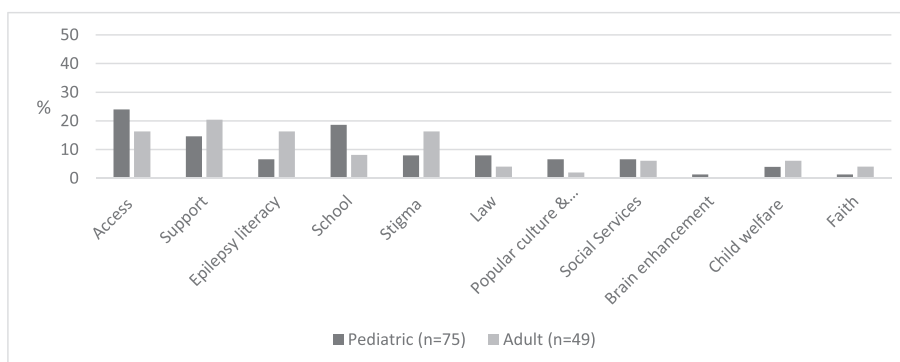


Fig. 7. Relative percent frequency of ELSI themes in pediatric and adult epilepsy news articles.

A few days after the surgery, Andi was sent home to Kitchener, Ont., and given time to recover. On Nov. 15, the DBS device was switched on and Dreher has since been testing different combinations of electrical pulses within set parameters she was taught by Andi's doctors - a process of fine-tuning aimed at determining which will work best for diminishing her seizures. Still, Dreher said the process involves some trial and error. (*The Hamilton Spectator*, 2018, "Kitchener family hopes 'brain pacemaker' can stop child's seizures after all else failed")

As in prior years, the issue of access to neurotechnologies was salient. There were reports of patients relocating to ensure their eligibility for coverage under different funds:

Sue Lomas is moving from Staffordshire in the hope another trust will fund a £14,000 operation to ease son Ryan's life-threatening epilepsy. (*Metro*, 2010, "Trust rejects op - so family moves")

There was also the arrival of a new kind of questioning, and discussion of ethical implication regarding the brain enhancing side effects of neural implants. Though not at the forefront of the majority of coverage, this represented an evaluative line of thinking that had yet to enter the discussion:

At the age of 4, suffering from seizures and severe attention and behavioral problems, Suzy had received an experimental new treatment: a neural implant that prevented her seizures and helped her to focus. As it turned out, the device also appeared to make her a prodigy at memorization, as her parents and teachers soon discovered. ... (*The Wall Street Journal*, 2012, "Bionic Brains and Beyond")

4. Discussion

Coverage of epilepsy and associated treatments has increased and diversified over time. Across international media with high readership; coverage trends based on therapies of interest are relatively similar and positive overall for both children and adults. The optimism for neurotechnology is consistent with literature on the media reporting of neurotechnologies for other conditions; however, neurosurgery has historically been a controversial topic [8,9]. Cabrera et al. conducted a content analysis of all types of psychiatric neurosurgeries, and found that historical ablative procedures, such as leucotomies, are largely reported with a negative tone across time and contemporary ablative procedures, such as stereotactic neurosurgery, were reported with negative tone in years prior to 2000 [8]. Similar findings by Diefenbach et al. support that the media that was once excited by the prospect of lobotomy, became negative a few years after its advent [10]. This is in contrast to our finding where, all forms of epilepsy therapies, including ablative procedures, are reported in a positive tone in a majority of the articles.

Ongoing issues of access to neurotechnologies and differing practices of insurers - whether private or public - in funding, often expensive, neurotechnological treatments may indicate a need for updated health policies. In the development process of government regulation for emerging neurotechnologies, entities like the Organization for Economic Cooperation and Development have recognized the importance of and continue to promote responsible innovation for neurotechnology [11].

5. Limitations

One of the limitations of this study is the challenge of identifying newspaper circulation information and therefore the fulfillment of that inclusion criterion. Furthermore, the Factiva database does not contain all newspapers that are available internationally, nationally, and regionally. Therefore, we only captured a sample of viewpoints and perspectives regarding epilepsy treatment that is being received by the public from the media. Further, we acknowledge that analysis of traditional online news is only one lens on the push of new knowledge and options about epilepsy to the public. Future work on the increasing role of social and digital media in the way that patients and their networks spanning different age groups get their information about epilepsy and neurotechnology would be invaluable.

6. Conclusions

Traditional news media has an important role to play in communicating advances in brain science to the public and can both influence and reflect public perceptions about epilepsy and treatment options. The optimistic attention to modern treatments, including neurotechnologies for children and adults, combined with concerns about access, underscores the importance of public engagement to ensure literacy about treatment options and realistic considerations for decision-making.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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