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### SUDEP: A Rhetorical Ecology of Grief

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SUDEP: A Rhetorical Ecology of Grief

by

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A master's essay submitted to the faculty of the  
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of the requirements for the degree

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**Abstract**

This essay explores the rhetorical ecology formed by the disabled community's digestion of the Epilepsy Foundation website. Specifically, I focus on the resources available for epileptics to learn about sudden unexpected death in epilepsy (SUDEP). The ecology around this discourse is not a positive one with which to engage, which can be detrimental to the physical health of some of its readers. The language is negative, and its interactivity is inappropriate – on an impressionable group of people, discourse must be carefully constructed to limit its negative impact, even when the topic is distressing.

This argument is practical as well as theoretical; I aim to use this essay to petition for the restructuring of the website.

## **Introduction**

This essay focuses on a rhetorical ecology that operates within a specific public: members of the epileptic community who have read the Epilepsy Foundation's website – in particular, the pages about sudden unexpected death in epilepsy (SUDEP). For an unlucky few, SUDEP's rhetorical situation extends from the communication of death and continues indefinitely, as they grieve lost loved ones and do their own research into SUDEP. However, there are *many* more individuals who interact with the information who do not have practical experience. I feel, for transparency's sake, that I must mention that I am part of the epileptic population without "practical" experience of SUDEP. Through the Epilepsy Foundation's website, community members (including epileptics' friends, family and caregivers) are confronted with SUDEP as they search for more positive things, like first-aid tips or the steps to getting a seizure-detecting dog.

Through my study of rhetorical theory and other scholarship, coupled with an exploration of the Foundation's website, I argue that the state of SUDEP communication to its public is harmful to the epileptic community – especially to impressionable members who are not searching for the information. I focus heavily on actual patients, rather than able-bodied members of the public. On the SUDEP pages, the Foundation has created a space in which toxic, collective despair breeds, and has the potential to drive off vulnerable patients and the recently-diagnosed from interacting with the Foundation's information. The Epilepsy Foundation's website houses some of the most comprehensive and accessible resources available to epileptics; we cannot afford to alienate anyone. Ultimately, the website needs to be restructured and the Foundation must take more care when engaging with SUDEP online.

## **An autoethnographical take**

For transparency's sake, I must note that I am a high-functioning epileptic. I started working with the Foundation soon after being diagnosed, at sixteen. I wrote for the website, I volunteer at events and have many friends at the Foundation. I was very proud of my involvement and continue to be. However, when I began studying the rhetoric they produce, I found myself disappointed. I remembered that when I was diagnosed, nearly everything on the website scared me. When I read certain things, like the SUDEP information, I would wonder, "Oh no, do I have to worry about this too?"

I was who I seek to protect by writing this essay. I was a vulnerable member of the community whose perception changed because of the Foundation's language. Like in many publications, the Foundation's rhetoric leans toward sensationalism, however unintentional – and so negative information becomes devastating. I don't want new patients terrified, especially because many of them cannot reason like I did. So yes, rhetorical ecologies in many digital spaces need exploring, but I am deeply embroiled in, and have a duty to try to change, this one in particular.

### **Foundational theory**

In *Philosophy and Rhetoric* (1968), Lloyd Bitzer proposes his model for a rhetorical situation. In his conceptualization, a rhetorical situation arises in response to an exigence, which he defines as "imperfection marked by urgency; it is a defect, an obstacle, something waiting to be done, a thing which is other than it should be" (p. 6). It is then given "rhetorical significance" by the situation, and somehow alters the reality of the exigence that prompted the situation. He writes,

Let us regard rhetorical situation as a natural context of persons, events, objects, relations, and an exigence which strongly invites

utterance: this invited utterance participates naturally in the situation, is in many instances necessary to the completion of situational activity, and by means of its participation with a situation obtains its meaning and its rhetorical character.

(p. 5)

This hyperlogical approach to constructing a rhetorical situation model does not lend itself well to complexity; unfortunately for Bitzer, rhetoric is complex. Bitzer's model "falsely links events, meanings, discourse, and resolution in a rigid and overly linear fashion. The outcome is a rhetorical situation that is dictated by events rather than the meanings residing in individual auditors and the rhetor" (Smith & Lybarger, 1996). This "continuing bias against the social construction of reality," hinders him in exploring the human aspect of discourse. Despite language being a human invention, Bitzer does not give the rhetor or audience a large enough role in the creation of the situation – an observation and criticism first made by Richard Vatz (1973). "Rhetors not only answer the question, they also ask it" (Grant-Davie, 1997, p. 264).

It is clear Bitzer's model is flawed. In addition to its oversights, it doesn't allow for growth within its confines, but that does not mean we cannot *alter* the model to give it that ability. Because of its simplicity, Bitzer's model is a clean scaffold upon which to build. In fact, scholars continue to manipulate it to accommodate the complexities of discourse as we understand them. Keith Grant-Davie (1997) and Jenny Edbauer (2005) are such scholars, and they of particular interest to this study; Grant-Davie for his "compound" rhetorical situations, and Edbauer for her rhetorical ecologies.

In Grant-Davie's 1997 "Rhetorical Situations and Their Constituents," he used Bitzer's model, and Vatz's (1973) and Scott Consigny's (1974) criticism of it, to create a new definition of a rhetorical situation: "...a set of related factors whose interaction creates and controls a discourse" (p. 265). However, this new definition is so vague that he makes the following

amendments: “I believe exigence...demands a more comprehensive analysis. Second...we need to recognize that rhetors are as much a part...as the audience is. And third, we need to recognize that any of the constituents may be plural” (p. 266). Grant-Davie’s progress with the Bitzer model paved the way for Jenny Edbauer’s 2005 interpretation, wherein she focuses on the impact an exigence, rhetor, audience and constraints (defined by Grant-Davie as “factors in the situation’s context that may affect the achievement of the rhetorical objectives” [p. 272]) can have outside the typical rhetorical situation. She calls this broader interpretation a “rhetorical ecology.”

### **The rhetorical ecology**

In “Unframing Models of Public Distribution: From Rhetorical Situation to Rhetorical Ecologies” (2005), Edbauer writes, “...rhetorical situations operate within a network of lived practical consciousness or structures of feeling. Placing the rhetorical “elements” within this wider context destabilizes the discrete borders of a rhetorical situation” (pp. 5). This destabilization transfers the focus from the situation itself to the way its message travels: circulation through a public. She leans on Michael Warner’s *Publics and Counterpublics* (2002) for her definition of a rhetorical public.

Warner makes a clear distinction between *a* public and *the* public. The word is often used to refer to the general public, or a governed public (Warner, 2002). However, within technical or professional communication, a public is “a space of discourse organized by nothing other than discourse itself...It exists *by virtue of being addressed*” (Warner, 2002, p. 50). Warner argues that the discourse that fashions a public is never limited to a single rhetorical situation, nor is it a collection of nodes that transfer information from one to the other. Warner (2002) states, “No single text can create a public. Nor can a single voice, a single genre, or even a single medium.

All are insufficient to create the kind of reflexivity we call a public, since a public is understood to be an ongoing space of encounter for discourse” (p. 62). For Edbauer, this is the most important part of his argument; Warner’s public is not static – therefore, her rhetorical ecology needs to be just as rhetorically nimble.

Edbauer uses Warner’s definition of a public to justify her theory and then uses the rhetorical ecology to criticize her colleagues’ “critiques and modifications” of Bitzer’s situation model. She asks, “Do theories of rhetorical situation allow us to theorize how ‘concatenation of texts through time’ help to create publics?” (Edbauer, 2005, p. 7). Her answer boils down to: yes, if you approach it from the right angle. She writes, “...the elements of a rhetorical situation can be re-read against the historical fluxes in which they move” (p. 8). Other scholars’ improvements to Bitzer’s model must remain static if they use Bitzer’s elements as he describes them. Meanwhile, with the help of Warner and other scholars, Edbauer’s ecology has the theoretical support it needs to let traditional rhetorical elements “simply bleed” (p. 9).

A rhetorical ecology – and by extension, its public – relies on circulation (that bleeding) to keep it afloat. Edbauer (2005) states, “we are never outside the networked interconnection of forces, energies, rhetorics, moods and experiences...a rhetoric emerges already infected by the viral intensities that are circulating in the social field” (p. 9). In other words, parts of an ecology are live before the rhetor has spoken and are ready to “infect” the message. Sackey, Ridolfo and DeVoss, in the first chapter of *Circulation, Writing and Rhetoric* (2018), expand on that thought, and bring it into the digital realm: “...circulation has helped cultivate new understandings about how rhetoric unfolds and acquires force in an increasingly digitally networked and globalized world” (p. 29). Ongoing study of circulation has cemented the idea that information moves dynamically through digitally-based ecologies. They state, “Such fluid-dynamics-thinking about



writing is especially important if we are to understand writing as a phenomenon driven by a technological code that bleeds into our everyday writing systems” (p. 28). Edbauer’s rhetorical ecology model, aligned with Warner’s publics, is well-suited to support this thinking, especially as the ecology contains organically-created, interdependent relationships that constitute the space in which they thrive. And according to the authors of that first chapter, “Making Space in Lansing, Michigan” (2018), that is exactly how the information within a public works.

### **Medical ecologies**

Judy Z. Segal, in *Health and the Rhetoric of Medicine* (2005), states “Rhetorical theory does not provide an exact procedure for teasing out the rhetoric of medicine, but it does suggest principles that can be used as instruments in the process” (p. 3). The following studies (including my own), lean on Warner and Edbauer’s theories, but it is the lived experience of a patient or researcher that allows us a window into the real rhetoric (and ecologies) of medicine. Theories only “enable and structure observations about human encounters. Each principle...is a strategy for interpretation in a world that...is saturated with rhetoric” (p. 4). We cannot rely entirely on the idea of a “rhetorical ecology” to help us explore medical rhetoric. To understand it and its processes, a reader, researcher or student must participate, because “Medicine is not only rhetorical as it is reproduced in published texts; it is also rhetorical as a system of norms and values operating discursively in doctor-patient interviews, in conversations in hospital corridors, in public debate on health policy, and in the apparatus of disease classification” (p. 3). Medicine produces rhetorical ecologies, but they are not *just* rhetorical ecologies – they often dictate how people live. I explore this concept further in this essay, when I examine the Epilepsy Foundation’s SUDEP communications’ impact on vulnerable members of its public.

Hannah Bellwoar's 2012 study of agency within medical communication, while not using the words "rhetorical ecology" outright, meshes well with Edbauer's ecological model. Bellwoar used a case study: a woman named Meagan. Meagan wants a child and is having a difficulty conceiving. Her consumption of medical resources or "health-related texts" reveals to the reader that a patient has just as much – if not more – agency than a rhetor (medical professional or otherwise). Though Bellwoar does not condense her findings into a useable model, she does tell us that the "traditional cultural frame considers agency to be...associated with medical professionals," even though patients are the most important actor in a health-based ecology. Patients must engage in what Bellwoar refers to as "literate activity" to stay healthy and informed. The term "literate activity" was first suggested by Prior in his book *Writing/Disciplinarity: A Sociohistoric Account of Literate Activity in the Academy* (1998), regarding graduate students' understanding of subjects and their socialization within the world of academia. Bellwoar, quoting Prior, writes "Prior (1998) says that writing is 'situated, mediated, and dispersed,' and... 'literate activity, in this sense, is not located in acts of reading and writing, but as cultural forms of life saturated with textuality.'" (p. 327). His statement aligns well with Edbauer's model; though literate activity is textually-based, those texts do not exist in a vacuum. Edbauer might say they are "infected."

Bellwoar applies this term to medical patients rather than graduate students and brings complexities to the table that she does not fully explore. That said, she *does* catalogue the many texts Meagan consumed. Bellwoar states, "...I want to point to the complex network of information and the prominence of multimodal texts...includ[ing] written documents but also images and other forms of documented discourse (e.g., television shows, movies, Web sites, Internet discussion boards, books, magazines, newspapers)." Meagan "encountered medical

worlds that were saturated with textuality...she was inundated with information from...official channels [and] various nonofficial sources...in effect, [she used] all of the varied spaces that she moved in and out of during her everyday life” (p. 327). Through these powerful descriptions of a fluid rhetorical landscape, Bellwoar illustrates that health literate activity is a fluid-dynamic circulatory system, like any other ecology.

Introducing the term “literate activity” into medical rhetoric is important, because it helps to legitimize the rhetorical ecology model within *applicable* technical communication.

Regardless of whether every facet of Edbauer’s theory is considered when it’s evoked, the phrasing may still help professionals who are trying to implement new care models for patients. After all, “Persuasion is a central element in many medical situations...the very terms in which persuasion takes place in health and medicine themselves condition outcomes” (Segal, 2005, p. 7). For example, if a more integrated, or ecological care model was recognized by the Epilepsy Foundation, medical comprehension rates would likely go up, and our community’s overall health would improve – a phenomenon evidenced in Walkup and Cannon’s care model study.

In 2017, Katie Walkup and Peter Cannon conducted a study of the operation of an “ecological care model” in a women’s addiction treatment facility, aiming to “reconsider...a technical communicator’s role in health communication...and redistribute power...among patients, mediators, and healthcare providers” (p. 108). They did not just focus on the patients’ understanding of themselves and their medical problems, but also helped the staff to “conceptualize their [mental health literacy] as an expanded network of health information professionals, rhetorical actions, and personal beliefs.” The study’s findings were positive: after the implementation of the model, women at the facility sought out information more, and what they read, they retained. The staff was retrained, despite differing opinions and practices, to

comprehend the women as individuals with complex needs, no matter their diagnosis. The study is an expert blend of rhetorical ecologies and a more physical, in-clinic care model, which focuses on members of the staff and their retraining. The latter part of the study resembles the recently-established “integrated care” model, which is a “systematic coordination of general and behavioral healthcare” (Lennox-Chhugani, 2018) that European facilities have been slow to adopt but quick to love.

Walkup and Cannon use Edbauer’s rhetorical ecology model as foundational knowledge. They write, “Drawing from Edbauer’s (2005) definition of *rhetorical circulation*, health ecologies distribute agency through networks of patients and providers” (p. 112). This definition appears in the middle of Edbauer’s argument for her radical augmentation of the rhetorical situation model (to form a rhetorical ecology). Edbauer acknowledges that a rhetorical situation model is valuable in many cases, but not when one factors in rhetorical circulation. Rhetorical circulation means “[that] public rhetorics do not only exist in the elements of the situations, but also in the radius of their neighboring events” (p. 20).

Walkup and Cannon are right to reference Edbauer. It is important to think of medical communication as a creator of rhetorical ecologies; it is almost as important as the implementation of an integrated care system or other care model in a facility itself. It is true (as Segal [2005] argues) that medical communication is special. However, it is especially unique when it comes to the creation of publics. Communities spring up around diagnoses (most visibly, certain cancers), and chronic diseases tend to have the strongest ones. Epilepsy is chronic, and the community is organized and often mobilized by the Epilepsy Foundation.

### **A difficult public**

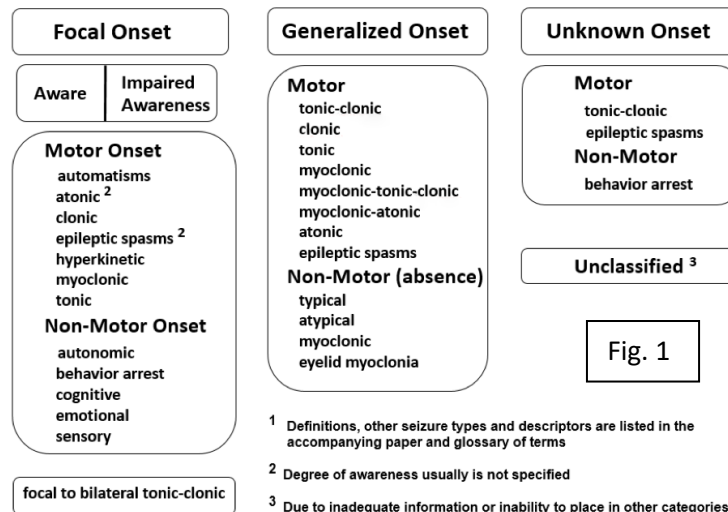
Because a public and its discourse are so intertwined, technical and professional writers must consider a communications' public just as they do the language itself. As argued by Warner (2002), a public exists "*by virtue of being addressed,*" not by a static category to which one belongs, like "tall people" or "brunettes." A public is largely text-based, however multimodal. Members of a physical or cognitive category may be predisposed to encountering certain discourse, but ultimately, publics are dependent on texts – and even more dependent on how individuals interpret them.

As Walkup and Cannon's study illustrates, publics generated by medical discourse come with many challenges. Diverse publics like theirs are difficult to navigate. For example, women in addiction treatment centers, though there may be similarities between them, represent a diverse group (Walkup & Cannon, 2017). The same can be said for the epileptic community, especially because the disorder implies a diversity in disability. Additionally, SUDEP communications' public consists of not only individuals with the disability, but also of some caregivers and loved ones. That said, the focus of this study will be on epileptics' interactions with the Epilepsy Foundation, and not on their able-bodied loved ones'.

Before the discourse discussion begins, we must quickly explore epilepsy. An epileptic can be many things. The word only means that someone has had more than one unprovoked seizure. An individual will not be diagnosed as an epileptic if they have seizures during a withdrawal period (from alcohol or any other addictive substance), or one that accompanies a non-neurological condition, like diabetes.

Seizures can manifest in many ways, depending on the type of epilepsy the patient struggles with. Figure 1 is a classification chart used to help classify the seizures of newly-diagnosed epileptics. Within these three categories – focal onset, generalized onset and unknown onset – there are 80+ different ways seizures affect the body

**ILAE 2017 Classification of Seizure Types Expanded Version <sup>1</sup>**



<sup>1</sup> Definitions, other seizure types and descriptors are listed in the accompanying paper and glossary of terms  
<sup>2</sup> Degree of awareness usually is not specified  
<sup>3</sup> Due to inadequate information or inability to place in other categories

(Shafer, 2010). For example, an absence seizure is characterized by stillness and blankness in the eyes, while tonic-clonic (often called grand mal) seizures are known for the violent muscle spasms they generate. Because the disease and its effects are unique to the individual, it is difficult to pinpoint general characteristics of the public, other than that epileptics have all had to contend with medical trauma. As the website says, “The word ‘epilepsy’ does not indicate anything about the cause of the person’s seizures or their severity.” In fact, “Many people with epilepsy have more than one type of seizure and may have other symptoms of neurological problems as well” (Sirven, 2014). The addition of other neurological difficulties only adds to the inconsistencies plaguing this public.

Also contributing to the diversification of the public is epilepsy’s debilitating effect on those who suffer from it. The location of a seizure event in the brain, and how far that electrical activity spreads, determines the severity of the damage an epileptic incurs. Some get lucky and become what the community calls “seizure-free,” which means they no longer experience the

events. However, many never reach that point, and there is no denying that epilepsy is dangerous, no matter where you are in your “seizure journey.” In April of 2014, the International League Against Epilepsy petitioned to change the classification of epilepsy from a disorder to a disease. “Even though epilepsy is a heterogeneous condition, so is cancer or heart disease, and those are called diseases. The word ‘disease’ better connotes the seriousness of epilepsy to the public” (Fisher et al., 2014). The danger is clear with just a cursory glance at the statistics: one in twenty-six people will have a seizure in their lifetime. Though the disorder occurs more often in the very young and very old, “epilepsy and seizures can develop in any person at any age” (Sirven, 2014).

This neurologically diverse public, all of whom are trying to contend with traumatizing information nestled in a rhetorical ecology of fear and grief, experience it as differently as they do their disease. Furthermore, poor medical literacy can exacerbate chronic conditions like epilepsy, most notably cancer and diabetes (Institute of Medicine, 2004), so accessibility must be at the forefront of any medical professional’s mind when writing for disabled publics. Ultimately, there is no way to understand this public completely, so a technical writer must create an ecology that supports the most impaired of us while keeping the information readable. The copywriters of the Foundation’s website, medical professionals or otherwise, struggle with this problem.

### **The Epilepsy Foundation’s SUDEP**

*Sudden Unexpected Death in Epilepsy (SUDEP) is said to occur when a person with epilepsy dies unexpectedly and was previously in their usual state of health. The death is not known to be related to an accident or seizure emergency such as status epilepticus. When an autopsy is done, no other cause of death can be found.*

*(Epilepsy Foundation, 2014)*

Sudden unexpected death in epilepsy (SUDEP) is treated with too much and too little care by the Epilepsy Foundation. The disorder is rare and under-researched, but that does not mean those with epilepsy can stay ignorant of the risk; perhaps that is why the Foundation has such difficulty discussing SUDEP. The inconsistent language used to describe the condition and its prevention would confuse any public. This confusion is only exacerbated by the public's lack of control over how they internalize the information, due to cognitive diversity. To some epileptics the reading can be traumatic, but others may digest it in a healthier way.

Sensationalism, hopelessness and negativity are common in the Foundation's communications – especially in the humanizing pieces and “SUDEP Stories” – but these qualities appear in informational resources as well. For example, in SUDEP resources that are advertised as objective, the Foundation links SUDEP to sudden infant death syndrome (SIDS), because of the lack of agency a patient maintains as they succumb to the disease. In many, this may establish fear – especially in those who have had children or are familiar with SIDS.

That said, the information *is* correct, but the problem is not its accuracy: it is its comparison of another, more sensationalized condition, to SUDEP. Just as in SIDS, SUDEP is near untreatable. Preventative measures can be taken but first you must perceive the threat, which is difficult to do, unless one's seizures are frequent. The Foundation does not provide useful information to help patients lower the risk of sudden death, saying, “Until further answers are available, the best way to prevent SUDEP is to lower your risk by controlling seizures” (EF, 2014). This is the objective for any seizure disorder treatment. If an individual is receiving medical care for their epilepsy, gaining control of their seizures is what they will work toward. For someone looking to prevent SUDEP specifically, the information under “How can I reduce



my risk?” on the Foundation’s SUDEP FAQ page will not be enough. Of course, this is not the fault of the Foundation; like many neurological conditions, SUDEP is difficult to research.

Because of this difficulty, the majority of SUDEP content refers to the statistics and aftermath of the disorder rather than prevention methods. Those at risk are typically at “young adult age (20-40 years old)” and have an “intellectual disability (IQ<70).” Additionally, “people taking a greater number of seizure medications may have a higher risk for SUDEP” (EF, 2014). These characteristics paint a very specific picture of someone who is likely to suffer from SUDEP. The usage of SIDS contributes to stereotyping by infantilizing victims and identifying them as Other, even to epileptics. Of course, the statistics are important; they alert anyone in that demographic to their heightened risk and should be listed. However, the way they are presented, under a section titled “Who is at risk for SUDEP?” might give other epileptics an unhelpful sense of relief. SUDEP can happen at any time, to anyone with seizures.

### **SARS outbreak and parallels**

The language of disease was similarly warped during the outbreak of SARS in China in the early 2000s. In 2009, Huiling Ding published “Rhetorics of Alternative Media in Emerging Epidemic: SARS, Censorship, and Extra-Institutional Risk Communication.” She “examine[d] how professionals and the public employed alternative media to participate in unofficial risk communication” around the first outbreak of SARS in China (p. 328). Clearly, a comparison to SUDEP communications is flawed in a few ways: first, a SUDEP victim has a pre-existing condition and is already part of a high-risk group; and second, the SARS outbreak far outstrips SUDEP in magnitude. However, the communication of SUDEP most definitely qualifies as risk communication, and its structure mimics the one around the first SARS outbreak. Despite my study’s focus on only one website (while Ding’s focuses on pieces of media from diverse

sources), SUDEP communication is similarly “decentralized, dynamic, and interactive,” and is “operat[ing] as a multilevel, multiplayer and multichannel process” (Ding, 2009, p. 329).

During the SARS outbreak, that risk communication flowed through distinct channels. A previous study of Ding’s (2007) revealed three main ones: the Chinese government’s classified communication, an official media channel and an unofficial channel which resisted media control. The Foundation’s communication also follows that three-channel structure. The channels include: empirical research/objective information, the Foundation’s humanizing work and the outpouring of grief in the comments section at the bottom of most SUDEP pages. Together, with the public’s engagement, the channels form a rhetorical ecology like Edbauer outlines in her scholarship. Though I have labeled them like static categories of communication, they interact and flow together just as any other medical ecology. My study might focus solely on one digital space, but the Foundation’s communications have a lot of power, especially on such an impressionable public. The space is also multi-modal, which gives the ecology more depth and allows for circulation *within* it.

Ding (2009) explains the application of Edbauer well: “[her] theory of rhetorical ecology conceptualized rhetoric as a public creation [with an] emphasis on circulation, movement, and transformation...” SUDEP’s ecology is not limited to the text posted by the Foundation – the ecology relies on the circulation of information within the public, and they can track its progress through individuals’ interaction with the site. Though the channels help create a robust ecosystem, they clearly interact poorly with one another. Seemingly objective evidence mixes with the Foundation’s humanizing pieces, and mourning parents and loved ones’ additions to the pages only highlight the fear generated by poorly-worded copy.

### **Website structure**

It is difficult to discuss the ecology without understanding the site's navigational structure, which heavily contributes to the looming presence SUDEP has on it. Figure 2

illustrates the click path to SUDEP's many resources. The topic is nested underneath the Learn tab and coupled with Early Death, which is the tab for suicide prevention. SUDEP could easily join suicide under the Early Death characterization, but there is so much information on SUDEP that it almost forms its own microsite. Perhaps that is why it has its own tab. The Foundation's use of just the acronym in the navigation is smart – to someone newly diagnosed, their unfamiliarity with epilepsy would hopefully deter them from clicking on it, just because it doesn't read like an urgent concern.

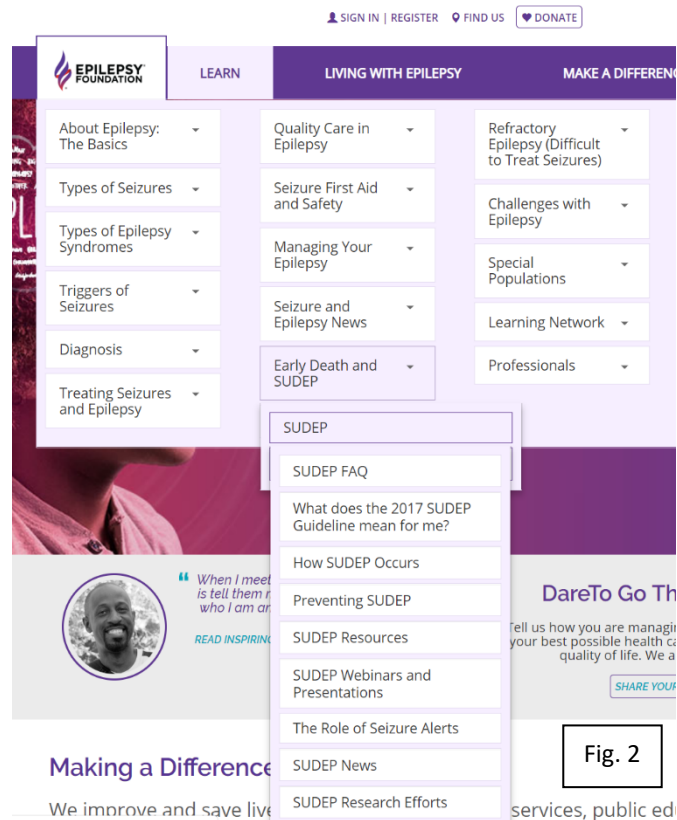


Fig. 2

The child properties (the navigation underneath the sub-navigation) under Early Death and SUDEP are overwhelming. The webmaster has elected to give every web page its own tab, rather than streamline the flow of information. For example, SUDEP, SUDEP FAQ, How SUDEP Occurs and Preventing SUDEP could all be on one page or microsite, under SUDEP Resources. The overdocumentation in the navigation leads to a dangerously long list when one is clicking around. The tabs are roll-over sensitive as well, so when a cursor moves over the tab, it opens, even if the user is not looking for that information. To visualize our ecology, it is easiest

to use the navigation. Though the categories it creates are somewhat arbitrary, just like any other user, we will also use it to explore.

### **Ecology and caregiver-centric language**

Empirical research and observation, softer articles and personal testaments are accessible from this menu. However, the tabs are misleading. There is less research than one would expect, even though the tabs are worded in a more technical style. Emotional writing and community-oriented calls to action are peppered throughout objective content. The first channel – the informational resources themselves – is where the SUDEP “boogeyman” begins to develop. The aforementioned typecasting of those at risk and negative language within research build a skeleton for the fear in the SUDEP ecology. On the first page of the SUDEP portion of the site, the “What happens?” section reads: “The person with epilepsy is often found dead in bed and doesn't appear to have had a convulsive seizure. About a third of them do show evidence of a seizure close to the time of death. They are often found lying face down. No one is sure about the cause of death in SUDEP” (Foundation, 2017).

There is not a lot of hope in the passage. This follows interviews with neurologists Orrin Devinsky, MD (the principal investigator for the North American SUDEP registry) and Jeff Buchhalter, MD, PhD (an expert in the usage of the ketogenic diet to treat seizures), who both stress how under-researched SUDEP is, and how detrimental it can be to “individuals and entire families.” One minute into his interview at the top of the SUDEP landing page, Devinsky states “[SUDEP] unfortunately is a very common disorder,” but later concedes that death by “many other factors [is] probably much...greater than SUDEP.” Even he, a respected member of the research community, contributes to the monster built in this rhetorical ecology. Yes, death is

awful, and yes, grief can be all-consuming, but right now, the language in these resources provides a foundation for all the fear around SUDEP.

Unlike the layered actors participating in SARS risk communication, there is no reliable alternative means to discuss SUDEP. The other websites cited on the SUDEP homepage cannot compare to the Foundation's wealth of research and connections, and if alternative media is introduced, a more direct line to bereaved parents, caregivers and friends could be detrimental. They already have too much influence on the website. If this were the state of the communication of SARS in China, it would be as if the citizens could both use and *participate* in the Chinese official communication (Ding, 2009). The three risk communication channels I have identified are built into the Foundation itself and are regulated. Articles have been approved by the Foundation's communications department and comments linked at the bottom of most SUDEP pages are moderated and replied to by Foundation employees. The ecology allows for the circulation of SUDEP communication, but the information is filtered, often for the consumption of community members without epilepsy: family, friends and caregivers. They hope to inspire action in *them*, rather than us, which is likely why SUDEP has become such a boogeyman in the community. The more human spaces on the SUDEP microsite, or the second channel, illustrate that.

Seven out of the nine sub-categories under the SUDEP tab provide more personal services, like grief support, or event promotion and volunteer opportunities. The content under any one of those tabs would work well to support my claim that this digital space is a toxic one, but SUDEP Stories, the last sub-category listed, does it the best. If you click the plus sign next to the tab, SUDEP Stories will open into an entirely new page with more categories. These mark individual landing pages that put faces to the dead and give parents an outlet for their grief.

These narratives, however well meant, keep the SUDEP conversation on the death, on the grieving, on the caretaker, on the parent. It is important to acknowledge their role in an epilepsy journey, but deaths should not be reduced to a narrative trigger that will only scare an able-bodied person into believing they must play savior.

For example, the story of John Paul Popovich (18 October 1996 – 18 December 2015), written by his parents, includes “For those reading this, if *your* child, loved one, or someone *you* know has had seizures, I urge *you* to be proactive and learn what *you* can about SUDEP. Make the inquiry with *your* doctor, take the time to learn about this *silent killer* that so few doctors will initiate discussion about. In doing so, *you* may save a life. *Our* son would have wanted that” [emphasis mine] (Popovich, 2015). The entire piece reads like this – there is not much about Popovich himself. We learn that he was a good swimmer and did well in school. But those are his only personality traits; he remains defined by the way he died. Just after we read about her son’s death, the mother writes, “And through that research, I learned about the many other SUDEP tragedies that have struck innocent families and changed their lives forever, just as it has changed our lives.” In all the SUDEP Stories, it is not the epileptic who changed lives, it is SUDEP and the neurologists who fail to mention it. As a parent, I imagine it would be tough to remain objective about the death of a child. However, that grief, spilled on a website page to catapult other parents into their own research, has shaped SUDEP communication. It is fear-inducing and in pieces like the Stories, desperate.

### **Reaction from the epileptic public**

The last channel in the SUDEP ecology is direct interaction with the public. The demographic changes depending on where you are on the site. On the bottom of the About Epilepsy: The Basics page, one commenter asks, “How does potassium effect epilepsy?” and

another writes, “I new something was wrong me immediately sat down nd had her get help ...next thing I know i wake up on the ground unable to move or feel my arms...Does it sound seizures?” [sic] There are many similar stories on the “basics” pages, many written by newly-diagnosed epileptics trying to understand their disease and commiserate with each other. However, when you migrate to the SUDEP pages, the comments get noticeably darker and are almost always written by grieving loved ones. At the bottom of the SUDEP FAQ page, Francine Read writes, “if we had been more educated we would have done so many things differently! Would it have made a difference? We will never know.” Just underneath, Judy Fett-Ward writes, “My daughter passed 7 weeks ago. She was found face down. We found this sight by googling if people can die from seizures...Prayers to all who suffer from seizures and they don’t have to endure what we done these past few weeks.” Perhaps the most telling of the environment, and the monster, that this rhetoric creates is a comment by Alireza [sic]:

Dear All;

I am a 30 years old man who is suffering from epilepsy for about 16 years. At first it started with a high fever when I wan 1 year old and after year everything was OK until my 14<sup>th</sup> year of life. From that day till now I am taking drugs and I think it is going to be normal. As I have seizure every year.

This SUDEP thing made me nervous and scare. Fro about 6 months I want to marry my fiancé and I do not know if I can wake up tomorrow or not. It is very disappointing for me and made me confused from 5 days ago. My doctors are having some researches with my MRA to survey if I can have an operation or not.

Please guide me. I am nervous and disappointed.

Kind Regards,

Alireza

Alireza, a member of the diverse public, one who has managed to make a life for himself despite persistent epilepsy, was disturbed by this information. He put his life on hold for SUDEP even though his epilepsy seems relatively controlled (he thinks “it is going to be normal”). Because of these SUDEP communications, Alireza is considering surgery, which will place him at a high risk for other cognitive complications. He has fallen victim to the grief and fear festering in SUDEP’s rhetorical ecology and exemplifies the reasons the SUDEP pages need to be rewritten.

### **Conclusion**

To change the ecology, we must circulate carefully-considered language, restrict the availability of a comments section and keep individuals with epilepsy at the forefront while writing for the Epilepsy Foundation. These precautions are necessary to prevent negative reactions like Alireza’s in other epileptics. A sudden change in a care regimen or a quest for a cure-all can permanently damage or end a life. It will be a process, but it is one that I intend to pursue.

The scholarly foundation on which this argument is built will help legitimize my claims and provide evidence in my favor when I bring my study to the Foundation (or the theory to another digital space). After all, Edbauer’s rhetorical ecology concept is already being used by medical professionals today. Therefore, I am confident I will be able to make changes to the rhetoric being used by the Epilepsy Foundation, and possibly to other websites read by vulnerable publics.



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