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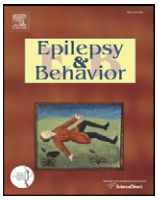

Review

Epilepsy stigma: What do we know and where next?[☆]

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ABSTRACT

Stigma is a major issue for people who develop epilepsy. Reducing stigma is a major focus of activity for the epilepsy patient support groups globally. In this paper, we introduce some key ideas and debates about the nature of and drivers for the stigma of epilepsy, including recent arguments about the need to frame analyses of the nature of epilepsy stigma within sociological debates about conflict and power. We then consider the role of the legislative process for redressing power imbalances that promote or maintain epilepsy stigma; and the value of tailored educational campaigns and programmes directed at stigma reduction. Finally, we consider the nature of 'difference' as experienced by people with epilepsy and how that difference translates into stigma; and provide evidence from a specific targeted intervention to combat epilepsy stigma that its reduction is an achievable goal.

1. Introduction

Stigma is a major issue for people who develop epilepsy. It has been argued that for many people with epilepsy (PWE), it is a more pressing problem than managing the clinical features of their condition, though the two are often inextricably entwined. Reducing stigma is currently a major focus of activity of epilepsy support groups globally. In this article, we introduce some key ideas and debates about the stigma of epilepsy and suggest some issues for future research and stigma reduction programs. Our section co-authors, Dee Snape and Paula Fernandes, then consider the nature of "difference" as experienced by PWE, how that difference translates into stigma, and how we can combat epilepsy stigma through targeted interventions.

The issues we consider in the first section are:

- The value of theoretical models of stigma in aiding understanding of the "lived experience" of stigma among PWE
- The cultural basis of epilepsy stigma and the implications for management
- The relationship of felt stigma to enacted stigma
- The importance of the concept of power
- The role of legislation in redressing the power imbalance between the targets of stigma—in this instance, PWE—and the perpetrators of such stigma
- The urgent need for high-quality evidence of the effectiveness of stigma reduction campaigns

2. Value of theoretical models about the nature of stigma

If the ultimate aim for PWE is to bring epilepsy "out of the shadows" [1], then an understanding of the drivers and different dimensions of stigma is important to direct appropriately targeted interventions. Sociological and psychological theories about why some illnesses, including epilepsy, are stigmatizing and others are not, therefore, become highly relevant. The starting place for any theoretical considerations of stigma is the work of the American sociologist Goffman [2], who defined the term *stigma* as referring to an attribute that is "deeply discrediting" and allows the stigmatized individual to be seen by others as "not quite human." There can be little argument about the relevance of this definition of stigma to epilepsy, a condition for centuries and across many different cultural settings almost universally defined as an "undesirable differentness" [3]. Consideration of why this should be so has led theorists to question whether epilepsy is stigmatizing because it represents some kind of tangible or symbolic danger [4]. Do people with a chronic

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illness such as epilepsy come to be viewed by society as people of low social value, because as a group they are unable to fully engage in the processes of social exchange and reciprocity [5]? Or does the total loss of control that occurs during seizures too closely represent a reversion to the primitive [6] or too strongly violate cultural norms regarding social interaction [7]? The answers to such questions are best explored through in-depth studies that seek to unpick precisely what lies behind stigma in particular sociocultural contexts and so to make the link between theory and practice.

Theoretical work has been valuable in delineating a number of key dimensions of stigma [8], two of which appear particularly relevant to epilepsy: (1) the visibility or concealability of the stigma and (2) the degree of its controllability. For a person who has epilepsy, good control of seizures makes their epilepsy invisible to others, rendering them "discreditable," rather than immediately "discredited" [2]. However, when they do occur, seizures are often difficult to conceal and tend to invoke fairly negative responses in those witnessing them. This controllability/visibility axis may be critical to the way in which people with epilepsy subsequently attempt to manage their condition, which may, in turn, have implications for their psychosocial health and for interventions aimed at improving it. Theoretical work also has importance for informing development of robust, quantifiable measures of all the relevant dimensions of stigma, necessary to document its prevalence and the degree to which it is reduced through targeted antistigma activities.

3. Understanding the cultural basis of epilepsy

Anthropological studies are important for highlighting the "relational" nature of stigma [8]: how culturally specific beliefs about the causes and prognosis of conditions of ill-health help to determine how they are managed both individually and collectively and the degree of the stigma attached to them (for some epilepsy-specific examples, see [9–12]). Such studies highlight that the social course of a condition such as epilepsy is "organised as much by what is at stake for participants in [their] local world as it is by the biology of the condition" [13]. If, for example, we look back in history at theories about epilepsy prevalent in the "local world" of Europe at the end of the 19th century, it is clear that these theories were highly significant in contributing to social policies that had major negative impacts at the time and the effects of which persisted well into the 20th century. Recent research tells us that the legacy of these old myths about epilepsy lives on. So, for example, in a study published in 2002, 22% of young Americans confessed to not knowing whether epilepsy was a contagious condition [14]; and in the Czech Republic, 29% of respondents to a survey published in the same year [15] still considered epilepsy to be a form of insanity. It is important to remember that these negative connotations about epilepsy have been documented not just for general publics, but also for key significant "others" such as health care professionals [16] and educational personnel [17]. Reis [18] comments that where the old stereotypes about epilepsy have faded (as appeared the case in her own anthropological study in The Netherlands), they seem to have been replaced by new ones, in which people with epilepsy are seen as introverted, less open than other people, and overanxious. In a study of public attitudes toward epilepsy in the United Kingdom [19], more than a fifth of those questioned agreed with a statement that "people with epilepsy have more personality problems than others."

Recently, one of us used "mini-ethnographies" [20] to explore sociocultural meanings of epilepsy in a non-European setting, namely, urban and rural China and Vietnam [21]. Our analysis highlights that despite deriving from highly "embodied" and therefore relatively nonstigmatizing paradigms of disease causality, epilepsy was nonetheless highly stigmatizing in both countries. Such stigma proved partly attributable to intensely pragmatic reasons: PWE simply represented a "bad bet" in terms of marriage, employment, and the degree of burden they placed on their families and communities. Further analysis of the data from China has also emphasized the importance of a particular local cultural phenomenon, the so-called "Rural Society," in defining the degree of stigma associated with epilepsy [22]. This kind of work directs us to the "whys" of stigma, not just the "how manys" captured in the numerous published studies providing percentage counts of negative attitudes and misattributions about epilepsy; and so is critical for determining content of proposed stigma reduction interventions.

4. The relationship of felt stigma to enacted stigma

The theoretical distinction between "felt" and "enacted" stigma [23] proposes a dichotomous construct in which felt stigma refers to the *shame* associated with being epileptic and the *oppressive fear* of encountering enacted stigma, whereas enacted stigma refers to actual episodes of discrimination against PWE *solely* on grounds of their condition. In a qualitative study involving 90 UK adults, Scambler and Hopkins reported that almost everyone experienced felt stigma, even if only intermittently, and that felt stigma was, *in effect*, a self-fulfilling prophecy, as one outcome of feeling stigmatized was that those doing so concealed their condition as much as possible and so denied themselves opportunities for testing whether what they believed to be true was actually true. Subsequent quantitative studies have supported both the felt/enacted dichotomy [24] and the high prevalence of felt stigma [25–28], which is not restricted to any particular culture, race, or society. The ubiquitous nature of the stigma that attaches to epilepsy and PWE, as evidenced by these studies, suggests a particular quality of effect, engendered by epilepsy, that is fundamental and transcends the boundaries that separate people from different backgrounds.

Because subjective experiences of stigma have been shown to be as threatening to health as objective acts of discrimination [29,30], it comes as no surprise that a link has been confirmed between felt stigma and psychopathology in PWE [24,26,31,32]. Most recently, Smith et al. [33] reported that felt stigma in PWE increases as self-efficacy and social support decrease and as worry about seizures increases, and Whatley et al. [34] reported that quality of life of PWE is significantly associated with both felt stigma and depressive symptoms. Implicit in such findings is the need for closer scrutiny of the process by which felt stigma is generated within PWE. Interesting though the reported studies are, a limitation of much of the work to date is its cross-sectional nature. Further work could usefully explore the "natural history" of stigma longitudinally from epilepsy onset and, hence, help illuminate whether it is a determinant or an outcome of other aspects of quality of life. Linked to this, because currently available evidence is not entirely consistent in its conclusions, the role of stigma in quality of life vis-à-vis other aspects of "having epilepsy" requires further elucidation: we need to know more about epilepsy as difference and the extent to which that sense of difference equates to stigma.

Turning to the issue of enacted stigma, it is almost certainly the case that to take one area of its impact, the low employment rates found in many countries among PWE compared with controls are (at least in part) a reflection of enacted stigma. *Indirect* evidence of this comes from studies such as those of employers' attitudes toward epilepsy. In recent work by one of us in the United Kingdom [35], 21% of employers reported that employing someone with epilepsy would be a major issue for them; and 44% described epilepsy as a condition that would cause them a high level of concern. Similar findings are reported by others [36,37]. The reasons given for taking this position were that epilepsy was more likely to lead to work accidents and work absenteeism (for which there is no supporting evidence), and that it was more likely to make other employees uncomfortable and increase the employer's insurance liability. Overall our knowledge of the prevalence and impacts of enacted stigma is less than that for felt stigma, for the simple reason that it has largely not been systematically documented [38]; and research that has been done has tended to focus on the “hard end” of enacted stigma, while neglecting its more subtle aspects [39].There is therefore a need for more robust research into the nature and extent of stigma as enacted against PWE.

It has been argued [40] that the differing clinical realities of epilepsy in developed and developing countries means that seizures will be more or less well controlled and so more or less visible, with possibly important implications for the way PWE experience felt and enacted stigma. Findings from previously cited studies [25–28] suggest that the root causes of epilepsy stigma are more deeply embedded than would be the case were it closely related to seizure control. Nonetheless, further investigation of the relative weight of these two separate dimensions of stigma within specific sociocultural contexts will be important for informing efforts at stigma reduction.

5. The importance of the concept of power

Returning to stigma theory, Link [41] has argued that it involves a number of constituents, one critical one being power. In Link's analysis, it takes power to stigmatize. The social exclusion and status loss experienced by those who are undesiredly different are the end products of a stigma process, in which human differences are first labeled as socially important and linked to negative stereotypes. Individuals so labeled then experience status loss and discrimination and, being denied access to the benefits of belonging to the dominant group, find themselves disempowered [42]. Following from Link's earlier work, Scambler [43] has recently revisited his concept of felt versus enacted stigma and argued that although it remains an important way of thinking about epilepsy stigma, his individually focused analysis needs to be framed within macrosociological debates about conflict and power. Thus, he concludes that epilepsy persists as a stigmatizing condition in capitalist economies whose norms of social “worth” create a situation of shame for the chronically ill and disabled. At the same time, he suggests, present-day more fluid and volatile cultures facilitate forms of identity politics [44] that allow those with “undesired differentness” to openly contest existing stigma relations and renegotiate their social position from one of being “discredited” to one of being “accredited.” Parallel analyses of conflict and power in other political contexts would be important for furthering understanding the nature of stigma.

Although Scambler himself does not consider that any clearly identifiable “epilepsy movement” has yet emerged, there are many in the world of epilepsy who would take issue with his claim. Epilepsy support groups globally have begun to rise to the challenge of stigma and are working hard to get across the message that PWE have the same skills and abilities as do others and deserve the right not to be discriminated against unfairly. Today, in the United Kingdom alone, there are more than 50 organizations for PWE and their families and carers. These associations have gradually been transformed from nonpolitical support groups into active campaigning groups, pressing for greater public education and understanding of the needs of PWE, better health and social care, and the eradication of stigma. Most notably, at an international level, the Global Campaign Against Epilepsy [45]—a joint initiative of the International Bureau for Epilepsy, the International League Aganist Epilepsy, and the World Health Organization—is working to reduce the stigma and, in turn, the economic and quality-of-life burdens of epilepsy. Its other major focus is on narrowing current treatment gaps, which in developing countries may be as high as 90%. These dual aims of improved treatment and enlightened attitudes have the potential, if realized, to impact significantly on the experience of stigma for those with the condition. Such attempts to shift the balance of power in favor of PWE do, we would suggest, need support through formal processes, as discussed in the next section.

6. Role of legislation for redressing power imbalance

The “undesired differentness” of epilepsy has long involved the application of formal rules and sanctions against affected individuals. Discriminatory laws are recorded as far back as 2000 BC, in the Babylonian code of Hammurabi. In Europe, antimarriage laws for people with epilepsy were enacted as recently as 1939 and were still on the statute books in some U.S. states until the 1980s. The Eugenics Movement legitimized some 60,000 sterilizations of PWE in the United States between 1907 and 1964 [46]; and a similar program of sterilization continued in Sweden until the 1970s. The instituationalization of PWE was legally allowed in several U.S. states until the mid-1970s, and epilepsy remained a bar to immigration in the United States and Australia until relatively recently. Today, in many developed countries, epilepsy is a “prescribed disability,” and people with the condition are protected in law. They are, however, still subject to legal discrimination, particularly with respect to employment and driving. It is probably fair to say that much of this has evolved in an “evidence-free zone” and reflects deep-seated fears and prejudices that border on superstition. Although some discriminations have a rational basis (as is the case with uncontrolled epilepsy and driving regulations), others are less defensible; for example, PWE are still denied the right to co-pilot a plane, even after more than a decade of postsurgical seizure freedom. In the United Kingdom, there is a long list of other occupations affected by statutory legislation. Similary, driving laws relating to epilepsy range widely in restrictiveness around the globe, from restoration of a driving license after 12 months of seizure freedom to a life-long ban.

Muhlbauer [47] has proposed a taxonomy of levels at which stigma operates: the internalized (the actions and reactions of the person possessing the stigmatizing characteristic); the interpersonal (the actions and reactions of significant others); and the institutional (the societal position taken, as embodied in its laws and statutes). It follows that stigma can be properly acted on only when stigma reduction initiatives target this last level alongside the first two. Efforts in the United Kingdom to address stigma through the legislative process are documented by Lee [38], though, as the author acknowledges, evidence of their effectiveness is still sparse. In other countries, also, legislative efforts in the form of acts such as the Americans with Disabilities and Australians with Disabilities acts aim to support people with epilepsy in challenging stigma. The problem surrounding such legislation is that it effectively pushes discrimination "underground," as it is impossible to legislate for the attitudes that underpin enacted stigma. Likewise, it is difficult to litigate with regard to discrimination when, for example, an employer needs state only that a candidate was not suitable for a particular position. We would suggest that in reality, such legislation may even be counterproductive, reinforcing stigmatizing concepts.

7. Reducing stigma through tailored interventions

It is important to remember that the stigma associated with epilepsy is not just a personal matter for individuals *with* epilepsy, but has important public health implications [48], such that reducing both individual and societal burdens of epilepsy should be a major priority of governments and health care systems worldwide. Its negative outcomes would seem easily to justify the cost of stigma reduction interventions. As discussed above, these would need to be targeted at specific groups (those targeted, those who target, and the social structural conditions that support stigma). They would also need to be informed by in-depth analyses to identify specific foci for the intervention. Some examples of the use of ethnographic approaches to do this have already been cited. Another good example is the community participatory work reported by Paschal et al. [49], in which PWE themselves set the agenda for future public education campaigns by recommending target audience-directed content and mode of delivery. It would be important for such studies to adopt replicable designs, using measurable outcomes and with formal evaluations in-built of what did and did not work, to aid understanding and future replication. Such studies do not come cheap but the potential gains are large.

Evidence is slowly accumulating that tailored interventions can reduce felt stigma in individuals with epilepsy, with knock-on positive effects for broader quality of life [33,34], and can improve public attitudes toward epilepsy [50,51]. There is also evidence of success in reducing disease-related stigma for a range of conditions of ill-health [52–54], from which important lessons can be taken. What is clear is that interventions need to take into account local conditions and be multifaceted in approach [55]. For example, it is now known that studies that aim to educate stigmatizers about the stigmatized are more effective when that educational activity is combined with contact between them, either directly or indirectly [56,57]. Further work is needed on how to sustain, for the longer term, any achieved attitudinal change; as well as on methods to incorporate stigma into assessments of disease burden and calculate the cost-effectiveness of initiatives to reduce stigma from both a societal and a personal viewpoint.

One of the major problems in addressing and attempting to reverse stigma is the idea that it has logical foundations. On the basis that fear is a fundamental cornerstone of epilepsy stigma, knowledge and understanding are powerful weapons against fear, and suitably framed education programs may reduce the stigma. Just as professional attitudes have been changed over time [16], so the attitudes of lay communities can be challenged and changed with the appropriate weaponry. Prescribed behavior, enforced by legislation, may influence overt behavior, but ignores the covert and deep-seated nature of stigma. This also needs to be recognized and targeted.

8. Conclusions

To conclude, we would suggest that the concept of “stigma” is likely to remain an important one for understanding the global social reality of epilepsy for the foreseeable future. There can be no doubt that for many people who develop it, epilepsy still acts as a “moral weight” they have to carry [58]; and for a sizeable proportion, stigma and discrimination remain matters of critical concern. In this article, we have tried to highlight the importance of exploring the concept of stigma and of efforts aimed at stigma reduction being theoretically and culturally informed; the need to explore and target the separate dimensions of felt and enacted stigma; the importance of methodologically robust trials of stigma reduction interventions, to provide high-quality evidence of their effectiveness; the moral imperative to support publicly focused antistigma campaigns through statute and the legal process; and the need for an increasingly politicized epilepsy “community” that continues to challenge the right of others to define “difference” as ”undesired.”

In the following two sections, the issue of difference is further addressed, as is the the potential for meaningful attitude change from targeted interventions. Both authors have followed directions little researched to date, but fully deserving of our continuing consideration.

9. Promising Areas of Research and Young Investigators

9.1. Dee A. Snape

The subjective experience of living with epilepsy: A narrative inquiry

9.1.1. Introduction. This qualitative study draws on the self and illness narratives of 14 adults with epilepsy to explore how the condition impacts directly or indirectly on daily living and life trajectories, and to represent the diverse nature and meaning of having epilepsy, including its stigma potential. What emerges from participants' stories is a discourse of disruption and difference, with epilepsy often imposing barriers to daily living and to maintaining a positive sense of self. As individuals communicate what is significant to them, attention to patient stories provides insight into how experience is constructed and evolves over time. Due consideration of such stories by health care professionals can offer direction in which intervention(s) can occur to ensure that the interests and needs of the individual with epilepsy are holistically considered and met.

9.1.2. Background.

It's not just the seizures; it's living with epilepsy.

This comment was made by one of my participants, Brenda, a 40-year-old single mum. It reflects the sentiments of many others in the study group.

Within Western contemporary medicine, epilepsy represents a common neurological condition, characterized by recurring seizures. Advances in the field of science and medicine, together with the increased effectiveness of antiepileptic drug regimes, have served to position epilepsy within a biomedical framework as a relatively benign condition with an excellent clinical outcome [59]. However, epilepsy is a condition that finds itself caught between competing discourses: the biomedical and the social [3]. That epilepsy is not just a clinical condition, but also a social label [31], means that the varied discursive constructions of epilepsy have the potential to shape the way in which the condition is known and experienced. For this reason, the current study draws on participants' self and illness narratives to explore how epilepsy impacts, directly or indirectly, daily living and life trajectories and to represent the diverse nature and meaning of having epilepsy, including its stigma potential.

9.1.3. The study. Narrative inquiry is one of many kinds of research gathered under the umbrella of qualitative research approaches [60]. It involves the collection and interpretation of stories; the central tenet is attention to the potential of stories to give meaning to events and experiences in people's lives [61–63].

Previous research on how individuals adjust to chronic illness has identified narrative as a mechanism for both illuminating these issues and enabling individuals to reevaluate and reconstruct coping with contingencies of everyday life and sense of self [64–68]. However, with few notable exceptions [69–72], the narratives of people with epilepsy have been overlooked. Consequently, the potential for health care professionals and others to learn from their unique stories and experiences has also been overlooked.

During the course of this study, I met with 14 adults with epilepsy, 7 of whom were female and 7 male. In-depth interviews were tape-recorded and transcribed verbatim. Participant stories, collected as data, became the unit of analysis and were identified using the four story components of Mishler's [73] theoretical model of Core Narrative. The four components—Orientation, Abstract, Complicating Action, and Resolution–are described in Table 1. This approach to analysis enables the integrity of the story to be maintained; subsequent examination can provide insights into lives in context [74].

9.1.4. Findings. Narrative encounters with participants reflected both their recent and more distant experiences of life with epilepsy. Although the stories told were uniquely individual, collectively a

Table 1
Core narrative model.

Story component	Description
Orientation	Describes the setting and the characters
Abstract	Summarizes the events or incidents of the story
Complicating action	Offers an evaluative commentary on events, conflicts, and themes
Resolution	Describes the outcomes of the story or conflict

dominant *plot* [75][1] was seen to emerge. The research identified that over time, the epilepsy narrative takes on a shared structure and content. For the adults with epilepsy in this study group, the *plot* takes the individual from a beginning of "discovery and diagnosis" through the process of "searching for a cause," "negotiating uncertainty and risk," and "striving for [but not always gaining] control."

As I worked to understand my participants' stories, I became aware that questions of the *meaning of epilepsy* were not always apparent at the point of diagnosis; rather, its implications for the lives of my participants emerged over time, as they attempted to reestablish themselves in the outside world in which they lived. Epilepsy often imposed barriers to daily living and to maintaining a positive sense of self; what emerged was a discourse of disruption. Stories of events highly meaningful to this portrayal of disruption included, for example, stories of discovery and diagnosis, seizure events and treatment; stories of symptom management and loss of control; stories of personal integrity across familial and work-related roles; and finally, stories of stigma and disclosure.

The physical and psychosocial impact of my participants' epilepsy was seen to negatively affect their lives and, as such, their identity—what Bury [65] refers to as *biographical disruption*. For some participants the disruption caused by epilepsy was seen to take its place amid other circumstances in daily living. For the majority, however, the uncertainty of epilepsy, characterized by a loss of control, was facilitative of biographical disruption. The following account serves to highlight the significance of the disruption of epilepsy in relation to identity:

> It's like bad enough when I go to the baths I have to go up to the fella in the baths and say that I suffer an epilepsy. So like while you're swimming they can keep an eye on yer in case anything happens. You know what I mean? So like a kid they have got to keep an eye on you, cos you don't know when you're going to have one [seizure]. Cos I could just be swimming and just like stop swimming … but as I say with taking kids yer normally down the shallow end anyway … but it doesn't make yer feel like too good does it when yer got kids looking after you? As I say with being the adult you should be the one looking after them … if something happens to them and I have one of mine [seizure] I can't look after them can I? [Ricky, divorcee and father to two young boys]

Ricky's seizures, as a symptom of his epilepsy, may not occur all the time, but his knowledge of their existence and their propensity for recurrence carries significance—they become the source of a negative sense of self, one that questions Ricky's public identity, both as an adult and in relation to his role as a father—significance that is not always overtly apparent to others. Ricky's account demonstrates how participants' stories reflect the social context in which disruption is experienced. Analytically, this helps us to consider *why* a story is being told, for we need to consider the point of a story if we are to give due consideration to what is at stake for the individual in terms of loss and gains [76]. For the adults with epilepsy in this study group, the point of the story often communicated the moral dimension of managing symptoms in parallel with daily life, in terms of both their actions and their experiences.

For example, social withdrawal and disclosure were often presented as a moral action, the purpose of which was to protect others from one's own behavior. Conceptions of guilt and shame served to shift the meaning of having epilepsy beyond its physical impact to "being a bad parent," "being a burden," or "being dependent on others." There was also the moral obligation to continually strive for competence and acceptance within familial, social, and work-related roles.

Ricky's account serves also to demonstrate that stories of disruption also function as stories of difference [64]. My participants' narratives repeatedly bear witness to how they view themselves in opposition to what they and others perceive as "normal" in relation to circumstance, age, and gender. Often coming into conflict with the accepted social order of things, as they perceived it, participants had to continually review and reconstruct their sense of self and social place as a means of regaining control. The instability between a desire for normalcy and the acknowledgement of difference required constant repair work, drawing on medical, relational, and cognitive resources.

9.1.5. Conclusion. Stories facilitate the revisiting of key moments in peoples' lives which enables us (as listeners) to consider the temporal elements of narrative; that is how experience is constructed and evolves over time. Aspects of the illness experience cannot be measured in isolation. For instance, what my own work has shown is that we cannot assume seizure frequency or work and social activity as fixed indicators of quality of life; stories weave together varying events and experiences that constitute a life. Different aspects of the epilepsy phenomena are brought into play through a sequence that begins before diagnosis and continues through the clinical encounter(s) and the resolution or progression of the condition. The narrative elements of such accounts are linked to the various life stages of the participants and their perceptions of the condition. For example, in the context of the current study, some participants portray epilepsy as a journey, or transition, in which lessons have been hard earned, whereas others view it as an end in itself. As such, stories reflect changes both in identity and in perception of time.

Stories are a part of everyday life and allow patients to communicate what is significant to them. I suggest that consideration of patient stories has the potential to provide new ways of understanding the experience of epilepsy, including its associated stigma, by illuminating points of tension in health care encounters and in daily living. Consequently, such stories offer direction in which intervention(s) can occur to address this tension and to ensure the interests and needs of the individual with epilepsy are holistically considered and met.

10. Promising Areas of Research and Young Investigators

10.1. Paula T. Fernandes, Ph.D.

An antistigma intervention for epilepsy

10.1.1. Introduction. Epilepsy stigma is a dynamic process present in many cultures and societies. In general, from the patient's point of view, the diagnosis of epilepsy brings about fears of being different and about the future. Perceptions are often negative, which compromises attitudes and impairs the patient's quality of life, reinforcing the stigma and thus closing a vicious circle.

The model of epilepsy stigma as a process allows the appropriate positioning of potential antistigma actions to minimize stigma perceptions. Our experience [77–92], derived from the Demonstration Project on Epilepsy, part of the Global Campaign Against Epilepsy (WHO/ILAE/IBE) executed by ASPE in Brazil, shows that language and attitudes toward epilepsy can promote changes in stigma perception.

In this context, the first important point emphasizes the difference between appropriate and inappropriate attitudes regarding a seizure in contributing to the stigma process. We performed a study [87] to evaluate whether an inappropriate attitude toward a person having an epileptic seizure contributes to the stigma found in society and whether an appropriate attitude helps to minimize it, and whether

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[1] Polkinghorne's (1988) definition of *plot*, "the logic or syntax of narrative discourse," is adopted for the current study and denotes a "linguistic expression that produces meaning through temporal sequence and progression" [75, p. 160].

stigma perception changes after an educational intervention aimed at changing attitudes.

10.1.2. Methods. We conducted this study in two steps:

1. Students from public and private schools in Campinas were divided into three groups: group 1 (G1) was shown examples of "appropriate" attitudes toward someone having an epileptic seizure; group 2 (G2) was shown examples of "inappropriate" attitudes ; and group 3 (G3) acted as the control. After completion of a pre-intervention questionnaire, an educational lecture about epilepsy was given.
2. Six months later, students answered the same set of questions again.

We used the Stigma Scale of Epilepsy (SSE) to evaluate stigma perceptions pre- and postintervention. The SSE is a specific quantitative instrument developed by our group and used to evaluate epilepsy stigma in the community [85]. This scale comprises 24 items about perceptions of epilepsy, each with a 4-point response set (1 = not at all, 2 = a little, 3 = a lot, 4 = totally). The SSE total score reflects the level of stigma perceived (0 = no stigma, 100 = highest level of stigma).

With this instrument, we were also able to perform a cross-sectional population-based survey in all regions of Campinas (an urban city located in the state of São Paulo, with approximately 1 million inhabitants) [79].

10.1.3. Findings. For the population-based survey, we interviewed 1850 people, and the results showed four main factors contributing to the stigma of epilepsy in the Brazilian context: gender, religion, social class, and school level. With respect to the effects of gender, women showed higher stigma perception compared with men. Regarding religion, the lowest score was observed for those who believed in spiritualism. In relation to social class, we observed a negative correlation between social class and stigma score: as social class rose, perception of stigma decreased. The same pattern was seen for educational level: as the level of education rose, the perception of stigma decreased.

Coming back to the attitude study, the results were interesting, as illustrated in Fig. 1. In step 1, the total score for perception of epilepsy stigma was similar in the two schools: 45 in the public school and 43 in the private school. However, there was a significant difference across the three groups [(ANOVA(2,179) = 3.25, $P = 0.04$); Tukey: $G1 < G3 < G2$].

On the basis of these results, it appears that people who were exposed to a positively framed educational session had lower perception of epilepsy stigma than those in the group exposed to a negatively framed session. We can, therefore, highlight the importance of provision of a correctly framed set of attitudes and correct information. We know that society's behavior can be more adverse than the seizures themselves, but we can change it.

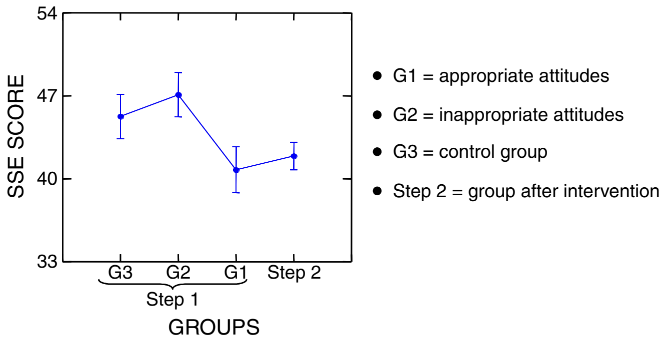

Fig. 1. General SSE score obtained by the schools in two steps. Adapted from Reno et al. [87].

The other important aspect in the stigma process is that of language expression. In our society, it is common to hear interchangeably the terms *person with epilepsy* and *epileptic*. The question then becomes: Do these two terms affect perceptions of epilepsy differently? In other words, in relation to epilepsy stigma, what is the advantage of using *person with epilepsy* instead of *epileptic*? To evaluate this difference, we studied adolescents from high schools in Campinas. We used two versions of a four-domain questionnaire (addressing work, school, and stigma perceptions) plus the SSE, which differed only in relation to the terms used: *people with epilepsy* for group 1 and *epileptics* for group 2. The results are illustrated in Fig. 2. In relation to SSE, the score was 45 (CI = 42.4–48.2, SD = 14.9) for group 1 and 49 (CI = 46.9–52.0, SD = 13.4) for group 2 ($T[212] = 2.151$, $P = 0.03$).

We can conclude from this that language expression does indeed influence the ideas and perceptions and has quantifiable consequences in the social stigma process. The use of "inadequate labels" hides the true identity of the person and can contribute to increasing their psychosocial difficulties.

10.1.4. Conclusions. Language expression and attitudes, in addition to correct information concerning epilepsy, are important factors for changing the perception of preestablished prejudices and beliefs and can contribute to minimizing the stigma perception within society. In this context, it is necessary that destigmatization campaigns are mounted on a repeated basis, to correct information and improve

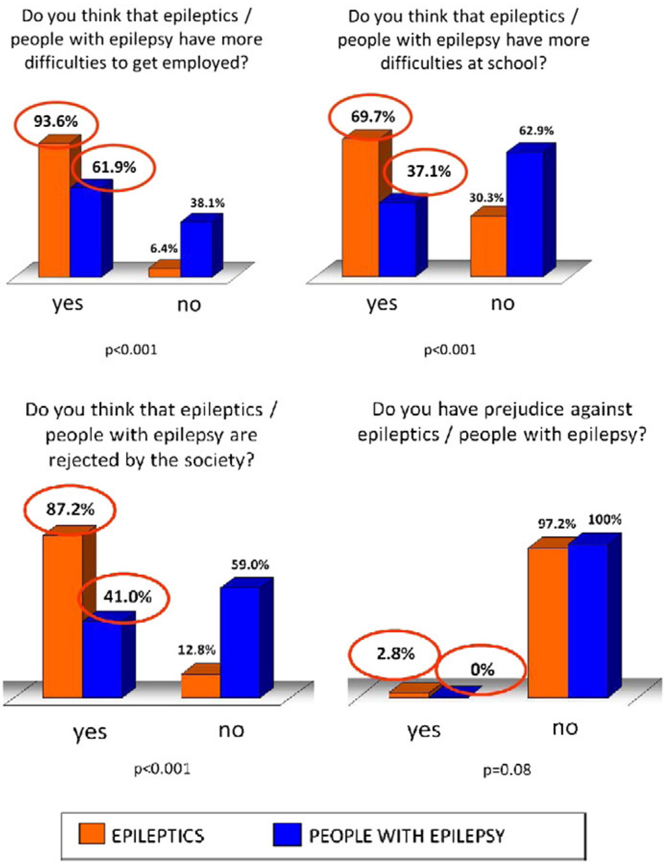

Fig. 2. Differences in reactions to the terms *epileptics* and *people with epilepsy*. Group 1 stated that 62% of people with epilepsy, and group 2 stated that 93% of epileptics, have more difficulties becoming employed ($P < 0.001$). Group 1 answered that 37% of people with epilepsy, and group 2 answered that 70% of epileptics, have more difficulties at school ($P < 0.001$). Group 1 answered that 41% of people with epilepsy, and group 2 answered that 87% of epileptics, are rejected by the society ($P < 0.001$). No one in group 1 said that they have prejudice toward people with epilepsy, whereas 3% of those in group 2 said they have prejudice toward epileptics ($P = 0.08$). Adapted from Fernandes et al. [77].

behaviors. These actions may help to deal with epilepsy stigma and to break the vicious circle. We believe that these actions help to place people with epilepsy into a more positive perspective.

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