Overcoming stigma: Performing the Workplace Experiences of People living with Epilepsy in France

Brenda Bogaert

In: The Routledge Companion to Performance and Medicine
ISBN: 9780367477738

This snapshot of practice details a theatre piece showing how people living with chronic illness may overcome stigma through performance. It will discuss a theatre show created by a group of people living with epilepsy in France in 2018. The show made use of forum theatre, an interactive methodology invented in the 1970s by Augusto Boal, that engages non-professional actors and audiences to articulate and rectify oppressions experienced in their daily lives (see Boal, 2008). The subject matter of a forum theatre show is usually one that is of direct relevance to the audience, so that they can relate to the central character who is being oppressed. In the methodology, the audience is first shown a short play in which a character encounters a form of oppression that they are unable to overcome. The play ends at this point, and then it is replayed with an invitation for an audience member to step up onto the stage and replace one of the characters (becoming what Boal calls a ‘spect-actor’). The audience member deviates from the script, trying different ways to resolve the oppression faced by the main character. More than one attempt can be made (including by different audience members), generating creative debate among the actors, spect-actor(s) and audience members. In the play discussed in this snapshot, a group of adults living with epilepsy used forum theatre methodologies to engage a range of audiences in addressing workplace stigma associated with this condition. The creative debate brought about by the methodology highlighted the importance of recruiting support persons in order to reduce workplace-related stigma.

The theatre troupe

The forum theatre troupe comprised seven individuals, six persons with epilepsy and one person interested in learning about epilepsy (myself as researcher). The group was made up of three women and four men; three of them were successfully employed, two were retired, and two were unable to work due to their condition. I had come to know the team while conducting ethnography on experiences of epilepsy with an independent patient group in Lyon, France that held their monthly meetings at an epilepsy research centre. I was invited to participate in the theatre project not specifically as a researcher, but as a fellow actor. However, I was also interested in using theatre as a research methodology, both in order to better understand the lived social experience of epilepsy through play, and also as a way to 'give back' to the epilepsy community, a way of helping to rectify the stigma I had uncovered in my research. Participating directly in the play's development and acting in the play gave me precious research insights, notably helping me to better understand the value of support persons in reducing stigma (Bogaert, 2020).

In terms of the play development, only two people (myself and another) had already done forum theatre, but none of us were professional actors or writers. Therefore, in order to develop the play, we did a workshop with an expert in forum theatre. She used theatre games to help the group to identify the most salient issues relevant to epilepsy stigma and then proposed a preliminary script which was further refined through a group discussion. While the role of the expert was pivotal in helping the troupe develop the script and acting skills, it was the actors themselves who identified what the themes would be and how to play these themes based upon their difficulties of living with epilepsy in society. In particular, the decision to focus on workplace stigma emerged directly from the workshop and the personal experiences of the participants.

Audience for the show

As the aim of the play was to build awareness and combat epilepsy stigma in society, a diverse audience was invited to see and participate in the show. The play was shown four times (twice in February 2018; once in June 2018; and once in February 2019). Firstly, as a test run, it was shown to an audience of about forty people living with epilepsy, their families, and neurologists during an epilepsy awareness day at a local epilepsy centre. A week later, we played to an audience of about thirty people at a local church, attracting a diverse public who were not necessarily informed about epilepsy. We also played to a group of about thirty medical students from France, Canada, and China as part of an international summer programme at the local medical school in order to help future doctors better understand the quality-of-life issues facing people living with epilepsy. Finally, at another epilepsy awareness day the following year, we played in the main street of the city in order to show our play to a wider audience.

Why talk about stigma in epilepsy?

Epilepsy is a serious chronic condition that is defined by recurring seizures. As the most common neurological condition after migraine, it affects up to fifty million people worldwide. The various manifestations of epilepsy – and seizures themselves – are highly individual and dynamic. Some manifestations of seizures, in particular tonic-clonic seizures, are seen as ‘impressive’ and ‘frightening’ by outsiders especially when the witness does not know how to help the person. Despite affecting various groups and people of all ages, having epilepsy has led to stigma throughout history, and unfortunately it has been hard to shake even today.

Epilepsy stigma dates back to Antiquity. The Greeks coined the word epilepsy (*epikgwia*), coming from the verb *epilambanein*, meaning ‘to seize, to possess’. They considered epilepsy as the effect of a miasma (bad air) that was thrown on the soul of sinners and this understanding led to stigmatization on the assumption that those with epilepsy were immoral (Magiorkinis et al, 2010). In the Middle Ages, it was associated with witchcraft. In the nineteenth century, more ‘scientific’ theories were formed, often drawing on the emerging field of psychoanalysis. These were no less stigmatizing, for example in the belief that there was such a thing as an ‘epileptic personality’ and that it was due to bad family character traits, such as alcoholism. The mistaken belief that epilepsy was a psychiatric condition also led to people with epilepsy being among the first patients when asylums were created. Nevertheless, this period also saw the emergence of neurology and epileptology, leading to successful treatments (Patel and Moshé, 2020). While this gradually helped both the medical community and society to recognize epilepsy as a neurological disorder (and helped many to better manage their seizures through successful treatment), it did not make epilepsy stigma entirely disappear.

Indeed, diverse misunderstandings persist in the popular imagination today, including seeing it as a psychological condition, psychiatric disorder or even as a contagious disease. For this reason, epilepsy stigma remains a problem worldwide and has a significant effect on the person’s quality of life, including in social relationships, in education, and in the workplace (Boer, 2010). Although certain professions are prohibited to persons with epilepsy due to the safety risks associated with seizures, in general seizure-related work accidents and absence rates are not substantial problems and most people living with epilepsy can integrate into normal working environments (Krumholz et al, 2016). In spite of this, numerous studies have linked epilepsy with higher rates of unemployment and underemployment, as well as greater difficulties in job retention (Smeets et al, 2007). Having epilepsy has also been correlated with job layoffs, being declared ‘unfit to work’, feeling shame for having the disease, and depression (de Souza et al, 2018). This is largely due to epilepsy stigmatisation and continued misunderstandings about the condition.

Identifying the problem and a potential solution through performance

How epilepsy stigma impacts the person in the workforce can best be seen through recurrent discussions in patient groups. For instance, at the support group in France that created the play, a heated topic was the decision of whether or not to tell one's future employer about their condition. This is a real issue for persons with epilepsy, as many find that when they disclose their condition at the interview, they are not hired. This remains hard for them to prove, as potential employers will not state this reason in their refusal letter and non-discrimination legislation such as the 2000 EU directive on equal treatment and the French labour code explicitly forbid this; however, it remains a reality for many persons with epilepsy. Whether or not they disclose their condition at the hiring stage, it is often necessary for persons with epilepsy at some point to discuss how their role may need to be adapted. These included padding sharp corners so the person would not hurt themselves if they have a seizure, allowing rest breaks or time off for doctor appointments, or adapting tasks and deadlines due to the side effects of medication, which may cause tiredness or concentration problems. In general, however, these changes are relatively minor and the person is usually able to continue doing their job well. However, even when employers were able or willing to adapt a post, this was often not well accepted or understood by their colleagues. Fellow colleagues frequently perceived that the person was receiving ‘special treatment’ or ‘exaggerating’ the seriousness of their condition, in particular because of recurring misperceptions of epilepsy as psychological. This made it difficult for these persons to do their jobs well but also integrate into the workplace with other colleagues, and they often felt isolated. According to the experiences of persons in the patient group, this stigma was particularly aggravated in lower-status, administrative jobs in the private sector which demanded a high level of efficiency. In higher status jobs, and/or in the public sector, some persons said employers were more willing to 'adapt' but this still took a willing and understanding supervisor. All in all, whatever the educational background or job status, persons in the patient group all faced some form of stigma in access to and inclusion in the workplace.

As problems with employment came up at nearly every meeting, some group members decided that it was not enough to discuss these issues among themselves, among those who already knew, understood or experienced it. They decided instead to do something about the stigma they experienced in the workplace. Their solution was the forum theatre show.

The epilepsy and prejudice show

The plot of the ten-minute theatre show takes place around a birthday celebration for Pierre, a person living with epilepsy. Two of his family members (Suzanne and Emma) and two work colleagues (Nathalie and Pascal), have come to his house party, where Pierre has just had a seizure and is resting in a chair. The first part of the theatre piece shows Emma advising Pierre on how to manage his epilepsy in a rather paternalistic manner. It is the second part of the play that addresses stigma in the workplace, when Nathalie and Pascal confront Pierre about the 'special treatment' he receives at work. Nathalie tells Pierre that 'everyone thinks you're a slacker' for taking sick days, while Pascal jokes that 'even when you're present, you have absences!'. When Suzanne comes to his defense, Nathalie dismisses his illness as 'purely psychological, all of that stuff. Get out a bit more, you'll see, it will do you good …'. A little later the two work colleagues confront Emma about their problems with Pierre …

PASCAL: Well, he's acting strange, that Pierre!

EMMA: Yes, how unlucky, on his birthday…

NATHALIE: I think it's more of a mental problem, those seizures…

EMMA: What?

NATHALIE: Well, it's obvious something's not right. We're his colleagues, we see him every day at work, and sometimes, he seems crazy. He says weird things…and then he doesn't even remember saying them! It's some kind of delusion. When it's like that, you should go see a psychiatrist. There are hospitals for that kind of thing.

PASCAL: Now wait a minute, you're exaggerating a bit…

EMMA: But it's not that…

NATHALIE: You know before, they used to think they were possessed, those… *(she mimics someone who is convulsing).* Personally, I don't believe it, but maybe there's some truth in it…

When Pierre and Suzanne rejoin the group, Natalie and Pascal reveal their naïve belief that epilepsy might be contagious:

NATHALIE: Ah, you see, when you want to…but wait, it's not contagious, is it? your thing? Because I looked it up on the Internet and I also asked some friends. They told me it could be contagious ...

PASCAL: Really, it's contagious? Oh no… I catch anything and everything that's going around. Here, Pierre, your gift…

He throws the gift at Pierre and runs away, putting his hands over his mouth.

In these excerpts from the theatre piece, we can understand how workplace stigma is perpetuated by Pierre's colleagues. First of all, there is the misperception that Pierre is inefficient, as he sometimes has to take sick days or work flexible hours. Even though Suzanne explains that the management have used these adaptations as an excuse to give him the 'dirty work', his colleagues continue to give him a hard time about this 'special treatment.' Rather than trying to understand why he may need reasonable adjustments they accuse him of being lazy, or that his condition is ‘in his head.’ By doing so, they perpetuate the idea that his condition is psychological rather than neurological. However, they also perpetuate ongoing misrepresentations of epilepsy as contagious. This may seem surprising, but several members of the theatre troupe reported experiencing this in their real life. In this theatre piece, we can therefore understand how living with stigma affects the person’s wellbeing in the workplace, in particular by isolating them from their colleagues.

Audience interaction and engagement

As noted above, in forum theatre, the audience does not passively watch the show, but also has the opportunity to become ‘spect-actors’, actively intervening to try to change the conflictual situation by replacing one of the characters. While the spect-actor in this case was not permitted to replace Pierre (the person oppressed) or the main oppressor (Nathalie), they were able to change places with either Suzanne, Emma or Pascal. In the showings, audience members brought several new ideas about how to combat stigma in the workplace. In one case, an audience member replaced Pierre's relative, Suzanne. In the scene when Nathalie makes a damaging statement about his moods and absences, rather than getting frustrated, the spect-actor decided to patiently explain to the two colleagues the side effects of seizures. She explained that they can cause fatigue and that that was the reason that he is sometimes very tired at work. She also told them that Pierre had found coping mechanisms after seizures occurred, such as deciding to do easier tasks while he recovered. Through this educational approach, the new Suzanne was able to show Pierre's colleagues that he was capable of working well despite his condition. This helped resolve the conflictual situation and the colleagues responded afterward in a more supportive way toward him.

In a second approach, Pascal was replaced by an audience member who took a different tactic. In the play, Nathalie is the vector of misunderstandings, notably by reinforcing the idea that epilepsy is a psychiatric condition, is contagious, or is simply ‘in his head.’ Pascal is more ambivalent, as he has not yet heard much about epilepsy. Therefore, rather than agreeing with or joking with Nathalie at each stage of the conversation, the new Pascal took the opportunity to ask Pierre about his epilepsy to better understand it. This immediately forced Nathalie to stop harassing Pierre. As a result, they both started to empathize with him about being giving the ‘dirty work’. The conversation then moved from teasing Pierre to discussing their problems with their jobs in sympathy with Pierre. They left the conversation understanding that epilepsy is a neurological condition that is not contagious, and that Pierre is their colleague, who also had a hard time at the office despite his need for reasonable adjustments.

Conclusion

In both of the solutions proposed by the spect-actors in the forum theatre piece, it was possible to resolve the conflictual situation and to overcome stigma in the workplace. It also gave new inspiration for those working to combat epilepsy stigma. In particular, the audience interventions showed that it was vital to involve a support person who could actively be involved in educating others about epilepsy. As the spect-actors showed, this resource person could either be a family member or a friend or those 'figures in the middle' who could also become supporters if they better understood the condition. Although this risks reducing the agency of the oppressed person themselves, in this case making Pierre passive, it makes the reduction of stigma a social responsibility rather than that of the individual. This case study shows that methodologies such as forum theatre can help raise awareness of the difficulties of living with chronic disease, but they can also bring forth creative change to entrenched problems.

References

Boal, A. (2008) *Theatre of the oppressed*. New edition. London: Pluto Press (Get political, 6).

Boer, Hanneke M. de. (2010) "Epilepsy Stigma: Moving from a Global Problem to Global Solutions". *Seizure* 19 (10): 630-36. https://doi.org/10.1016/j.seizure.2010.10.017.

Bogaert, B. (2020) "Untangling fear and eudaimonia in the healthcare provider-patient relationship", *Medicine, Health Care and Philosophy*. doi:10.1007/s11019-020-09956-1.

Krumholz, A., Hopp, J.L. and Sanchez, A.M. (2016) 'Counseling Epilepsy Patients on Driving and Employment', *Neurologic Clinics*, 34(2), pp. 427–442. doi:10.1016/j.ncl.2015.11.005.

Magiorkinis, E., Sidiropoulou, K. and Diamantis, A. (2010) 'Hallmarks in the history of epilepsy: epilepsy in antiquity', *Epilepsy & Behavior: E&B*, 17(1), pp. 103–108. doi:10.1016/j.yebeh.2009.10.023.

Patel, Puja and Solomon L. Moshé. (2020). “The Evolution of the Concepts of Seizures and Epilepsy: What’s in a Name?” *Epilepsia Open* 5 (1): 22-35. https://doi.org/10.1002/epi4.12375.

Smeets, V.M.J. *et al.* (2007) ‘Epilepsy and employment: Literature review’, *Epilepsy & Behavior*, 10(3), pp. 354–362. doi:10.1016/j.yebeh.2007.02.006.

de Souza, J.L. *et al.* (2018) ‘The Perceived Social Stigma of People with Epilepsy with regard to the Question of Employability’, *Neurology Research International*, 2018, pp. 1–5. doi:10.1155/2018/4140508.