



Epilepsy stigma and stigma by association in the workplace

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ABSTRACT

In the first experimental study of epilepsy-based discrimination in the workplace, we examined the influence of stigmatization on the workplace outcomes of hypothetical employees who were associated with epilepsy, but who did not have epilepsy themselves (stigma by association). Participants (40 women, 16 men), acting as employers, evaluated one of six randomly assigned employee work portfolios that were identical except that the employee was either male or female and had taken leave during the past year to care for a child with either epilepsy or asthma, or for whom no leave was mentioned. They then evaluated the employee and made recommendations concerning the employee's workplace rewards (promotion, raise) and penalties (job termination). Work quality evaluation was similar across conditions. However, parents of a child with epilepsy received fewer workplace rewards and greater workplace penalties than did employees in the other conditions. Implications for mental health and antibias interventions are discussed.

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1. Introduction

Workplace disadvantages for people with epilepsy have been well documented for more than 30 years [1–5]. Both unemployment and underemployment rates are typically higher for people with epilepsy than for the general population [6–8]. Furthermore, the higher rate of unemployment for people with epilepsy in the United States has remained virtually unchanged across recent decades [9]. Our research concerns the contribution of *epilepsy-based stigma* to these lesser workplace outcomes. Stigmatization is defined as the attribution of socially devalued characteristics to members of certain groups [10]. Writings in the 13th through 19th centuries provide ample evidence for the stigmatization of people with epilepsy as sick, unclean, sinful, possessed, and/or contagious [11]. More recently, research has found that people with epilepsy are often stereotyped as being aggressive, antisocial, mentally retarded, unattractive, introverted, overly anxious, and undesirable employees [4,12,13]. We contend that this stigmatization has implications for the workplace outcomes of individuals with epilepsy.

Field studies investigating epilepsy-based workplace disadvantages have contributed to our understanding of workplace barriers faced by individuals with epilepsy. In a study of employers from several hundred companies in the United Kingdom, 72% of respondents reported that most or all of the positions in their company would be unsuitable for a person with epilepsy [4]. However,

employers in these field studies generally have not listed stigmatizing beliefs as a reason for their disinclination to have individuals with epilepsy work at their companies. Instead, employers have frequently cited factors such as concerns about employee safety, social discomfort of co-workers, and lowered productivity as reasons for their preference not to hire people with epilepsy [2,4,6]. Arguably, some jobs might indeed present safety concerns for the subset of individuals with epilepsy who have frequent, severe seizures. It is reasonable to question whether epilepsy-based workplace bias would be eliminated if concerns about employee safety, productivity, and co-worker apprehension were removed. However, we predicted that individuals associated with epilepsy would continue to face disadvantages in the workplace, even if the aforementioned concerns were removed, due to epilepsy-based stigma.

In the first experimental study of the workplace consequences of epilepsy-based stigma, we empirically assessed whether poorer workplace outcomes would be obtained for hypothetical workers with performance records comparable to those of their peers who do not have epilepsy themselves but are merely associated with epilepsy. Specifically, we examined whether workplace discrimination would be experienced by a *parent* of a child with epilepsy, despite epilepsy-based workplace safety, productivity, and social discomfort concerns being inapplicable to them. We investigated whether individuals who had taken leave to care for a child with epilepsy would experience *stigma by association* and be less likely to earn a promotion and raise, and more likely to be recommended for job termination, compared with identically performing employees who had taken leave to care for a child with asthma or who had not taken leave at all.

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Goffman proposed that individuals who are not themselves members of a stigmatized group may nonetheless become subject to the same social rejection and discrimination experienced by those in the stigmatized group by being in some way associated with members of the group (e.g., through friendship) [14]. Stigma by association (or associative or courtesy stigma) is well documented. Psychiatric nurses are often stigmatized by their peers as being less logical, less skilled, more introverted, and more dependent than nurses from other specializations, seemingly based on their association with people who have mental disorders [15]. Stigma by association has also been found for family members of someone with a mental illness [16] or who is living with HIV [17], parents of a child diagnosed as mentally retarded [18], caregivers of a person with Alzheimer's disease [19], romantic partners of a person with a physical disability [20], and heterosexual male friends of gay men [21].

Kulik states that, in stigma by association, perceivers' mental representations of the stigmatized person and those closely linked to him or her have become connected through "associative pathways" [22]. Because of this mental association, negative characteristics ascribed to stigmatized persons automatically come to mind when perceivers consider people with whom they have become associated. Perceivers may then automatically, and often unintentionally, transfer their cognitively salient negative evaluations of the stigmatized person to those associated with that person. Thus, although one might expect the obstacles faced by individuals stigmatized by association to be less than those faced by stigmatized individuals, research has found that the stigma-based challenges that the two groups face generally are quite similar.

Isolating the unique effects of stigma in field studies is often difficult, given that responses on self-report measures, such as surveys used to measure employers' attitudes, may be influenced by social desirability concerns. It is reasonable to assume that most employers are aware that not hiring individuals based on their epilepsy status is illegal and therefore would be reluctant to express such a bias. Self-report measures are also limited in that individuals may not always be consciously aware of their biases. For example, many individuals who consciously report being nonprejudiced show evidence of strong biases on implicit prejudice measures [23]. Consequently, biased evaluations caused by an employer's epilepsy-based stigmatization may occur despite the employer's awareness. Furthermore, bias-related negative work outcomes may be difficult to conclusively identify. Given the variation in relative work strengths and weaknesses from employee to employee, it is difficult to identify "comparable" workers with and without epilepsy whose relative workplace outcomes might be compared.

Our experimental methodology allowed a clearer comparison between the workplace outcomes of identically qualified hypothetical employees who were and who were not associated with epilepsy. In an adapted paradigm [24], participants were asked to place themselves in the role of an employer tasked with evaluating an employee and making recommendations concerning the employee's future in the company. They were then randomly assigned to evaluate one of six hypothetical employee work portfolios that were identical with two exceptions. First, given that prior research has found that women are penalized more than men for taking leave, we varied the employee's name to indicate gender [24]. Second, the portfolios varied in that they indicated that the employee had taken leave during the past year to care for a child with either epilepsy or asthma or contained no mention of a leave being taken. Asthma was selected for a comparison condition given that breathing disorders such as asthma are less stigmatizing than epilepsy in workplace and school settings, but do not differ from epilepsy in degree of "special physical care" perceived to be necessitated by the condition [4,25].

We then examined the effects of these portfolio variations on evaluations of the employee's work quality and allocation of workplace rewards and penalties to that employee. Consistent with our stigma/stigma by association framework, we predicted that the stigma of epilepsy would negatively impact the workplace outcomes of hypothetical employees who had taken leave to care for a child with epilepsy, even though the most common epilepsy-related concerns expressed by employers (e.g., employee safety) were not applicable to them. Specifically, we predicted that these hypothetical employees would be less likely to be recommended for a raise or promotion and more likely to be recommended for firing than employees with identical work records who had not taken a leave or who had taken a leave to care for a child with asthma. We suspected that hypothetical employees who took leave to care for a child with asthma might also achieve poorer workplace outcomes than those who had not taken leave. However, given that asthma is less stigmatizing than epilepsy, we did not expect their negative outcomes to be as pronounced as those found for parents of children with epilepsy.

We also examined whether association with a child who has epilepsy would impact perceptions of the employees' work quality and whether such differential perceptions would account for any disparities in workplace outcomes across conditions [24]. We predicted that having taken leave to care for a child with epilepsy would clearly impact employees' workplace rewards and penalties, but were more tentative in our prediction that such diminished outcomes would be associated with poorer work quality evaluation. We predicted that the stigma (by association) of epilepsy might negatively impact associated employees' outcomes, even when the quality of their work was evaluated to be as strong as that of their peers.

2. Method

2.1. Participants

Participants were 40 women and 16 men enrolled in an introductory psychology course at a predominately commuter campus in which the majority of students work part- or full-time (Institutional Review Board Approval H05268). Participation was one means to fulfill a course requirement. The study was advertised on a university website in which research projects in need of participants are described and through which students can sign up for the projects in which they would like to participate. Participant age ranged from 18 to 53 years ($M = 21$, $SD = 6.90$). Twelve participants identified as Caucasian, 26 as African-American, 5 as Latino, 1 as Asian, and 3 as Multiracial/Other. Data for 9 participants were excluded because of their failure to demonstrate at least minimal knowledge of epilepsy (see Knowledge of Epilepsy under Materials).

2.2. Procedure

Participants were seated at individual computer stations. At the start of the session, a female experimenter asked participants to read and sign informed consent documents. Participants then read computerized instructions that they were to assume the role of an employer in evaluating the work of an employee. The computerized instructions referred the participants to a binder placed beside their keyboard that contained an employee work portfolio. Each participant received one of six randomly assigned portfolios that were identical except that the employee was either a man or a woman and either had not taken a leave during the past year (No Leave condition) or had taken a leave to care for a child with either epilepsy (CWE condition) or asthma (CWA condition). Participants were allowed 10 minutes to review the portfolio.

Participants were then asked to complete the Good Businessperson Scale [24], which assessed their perceptions of the quality of the employee's work and their likelihood of recommending the employee for workplace rewards (raise or promotion) or penalties (job termination). Following this task, participants were asked to complete a battery of questionnaires presented as unrelated to the previous measure. These questionnaires included measures of participants' knowledge of epilepsy and attitudes toward epilepsy and asthma, as well as a demographic survey. The researcher then debriefed and thanked the participants.

2.3. Materials

2.3.1. Employee portfolio

Each participant, playing the role of an employer, was provided with a binder that contained the employee work portfolio of an advertising sales manager whom they were to evaluate [24]. Documents within the portfolio included the employee's job description, resume, recent performance appraisal, and timesheet. These materials were modified versions of actual employee documents obtained by the researchers. They were designed to reflect a strong, although not stellar, pattern of work performance by the employee. In the CWE and CWA conditions, the work portfolio binders also included the following three additional documents: an official Family and Medical Leave Act (FMLA) leave request from the employee, a brief letter from the employee explaining the reason for the leave (to care for their child who had either epilepsy or asthma) and the requested dates that they would be on leave (12-week duration), and a letter from the employee's human resources director indicating that the leave had been approved.

The position of advertising sales manager was selected for the present study because of its comparable representation of men and women [26] and its utility in previous research in which designation of a gender-neutral occupation was desired [24,27]. Employee gender was indicated by the first name provided on the employee's resume (Sharon or James) and the use of either masculine or feminine pronouns in references to the employee. These particular first names had been found in previous research to connote similar demographics, such as age [28]. Other than employee gender and leave condition, the employee work portfolios were identical.

2.3.2. Good Businessperson Scale

After reviewing the employee work portfolio for 10 minutes, participants were asked to evaluate the employee's work quality and to make recommendations concerning the employee's workplace outcomes. They were asked to indicate these assessments and recommendations by completing the Good Businessperson Scale ($\alpha = 0.89$) [24]. On this questionnaire, participants indicated their degree of agreement with each of 17 items using a 1 (strongly disagree) to 7 (strongly agree) scale. Items constituting three separate subscales are dispersed throughout the questionnaire. The Work Quality Evaluation subscale contains 13 items, such as "This person is an effective manager," "This person is a strong leader," and "This person has good customer skills." The Workplace Rewards subscale contains the items "I would give this person a promotion" and "This person does *not* deserve a raise" (reverse-scored). The Workplace Penalties subscale comprises the items "If this person does not address his/her shortcomings, he/she will be fired" and "If I were this person's boss, he/she would be fired."

2.3.3. Attitudes toward People with Epilepsy Scale

We created a seven-item, self-report scale to assess three perceptual factors suggested by previous research to be related to

workplace disadvantages for people with epilepsy [4,6]: social discomfort in the presence of people with epilepsy, belief that people with epilepsy are less competent and less productive workers, and fear that employing people with epilepsy will constitute a financial burden on the company. The Attitudes toward People with Epilepsy (APWE) scale ($\alpha = 0.85$) comprised four items adapted from Bogardus' Social Distance Scale [29] to assess the social discomfort factor (e.g., "I would feel comfortable being in close proximity with a person with epilepsy," "I would be comfortable having lunch with someone with epilepsy"); two items assessing the workplace competency/productivity factor ("People with epilepsy are equally productive at work as are those without neurological disorders," "As a manager, I would entrust a decision-making task to a person with epilepsy"); and one reverse-scored item assessing the financial burden factor ("I think that a person with epilepsy can constitute a financial burden to his/her employer").

As a manipulation check, a second survey, the Attitudes toward People with Asthma (APWA) scale ($\alpha = 0.79$) was administered to assess whether the previous finding that respiratory disorders are associated with less stigma than are epilepsy disorders would be replicated with the present sample [4]. The APWA scale was identical to the APWE scale with the exception that the word *asthma* replaced the word *epilepsy*. Because of a technical error, data for the APWA scale were collected from only 16 participants. Nonetheless, the expected pattern of more negative ratings on the APWE versus APWA scale was obtained (M 's = 5.85 and 6.44, respectively); $F(1, 15) = 17.56, P < 0.001, \eta^2 = 0.54$.

2.3.4. Demographic survey

Participants were next asked to provide basic demographic information such as their age, gender, and ethnicity. They were also asked to indicate their college major and to indicate the number of prior experiments in which they had participated (variables that proved to be unrelated to the study findings).

2.3.5. Knowledge of epilepsy

As their final question, participants were asked to provide a brief definition of epilepsy. Coders blind to participants' experimental condition coded these written responses on a 3-point scale, with a score of 3 representing clear knowledge of the nature of epilepsy and a score of 2 representing responses that suggested vague or incomplete, but not inaccurate, understanding of epilepsy. A score of 1 indicated that the person reported no knowledge of epilepsy or erroneously defined a condition other than epilepsy. Data for the nine participants who scored a 1 on the epilepsy knowledge (EK) question were excluded from the present data set, given their lack of even a minimal knowledge of epilepsy.

3. Results

3.1. Preliminary analyses

Our primary research interest was to assess the relationship between employee leave condition (no leave vs leave for child with epilepsy or asthma), epilepsy knowledge and attitudes, and worker evaluations and outcomes. In addition, we assessed the effects of participant ("employer") and target ("employee") gender, given that these variables had been found to moderate the effects of employee leave (with no disorder specified) on workplace outcomes [24]. However, in contrast to the findings of previous research in which health condition was not a factor, neither employee nor employer gender was found to significantly moderate employee evaluations, rewards, or penalties. Consequently, the remaining analyses focused on our key epilepsy-relevant measures.

3.2. Does taking leave to care for a child with epilepsy negatively impact hypothetical employees' workplace evaluations and outcomes?

We conducted a MANOVA of the hypothetical employees' Work Quality Evaluations, Workplace Rewards, and Workplace Penalties, as a function of leave condition—No Leave, Child with Epilepsy (CWE), or Child with Asthma (CWA)—with Epilepsy Knowledge and Epilepsy Attitudes (EK and APWE scores) included as covariates. No significant effects were obtained for either Epilepsy Knowledge, $F(3, 40) < 1$, or Epilepsy Attitudes (APWE score), $F(3, 40) = 1.54$ ($P = 0.22$). However, the MANOVA yielded a significant omnibus effect for leave condition: $F(6, 82) = 2.36$, $P < 0.04$, $\eta^2 = 0.15$. Given the significance of this overall finding, we next examined the univariate effect of leave condition on work quality evaluations. Although associated with an appreciable, albeit small, effect size ($\eta^2 = 0.11$), the effect of leave condition on work quality evaluations did not reach statistical significance: $F(2, 42) = 2.67$, $P = 0.08$ (No Leave $M = 4.51$, CWA $M = 4.82$, CWE $M = 4.04$).

In contrast, significant results were obtained on the univariate tests for both Employee Rewards, $F(2, 42) = 3.19$, $P < 0.05$, $\eta^2 = 0.13$, and Employee Penalties, $F(2, 42) = 3.61$, $P < 0.04$, $\eta^2 = 0.15$. Follow-up contrast analyses revealed biases against employees who took leave to care for a child with epilepsy but not those who took leave to care for a child with asthma. Workplace outcomes for employees who did not take leave and CWA employees did not significantly differ: for Employee Rewards, $F(1, 30) = 2.00$, $P = 0.17$ (M 's = 4.32 and 3.76, respectively); for Employee Penalties, $F(1, 30) < 1$ (M 's = 3.65 and 3.25, respectively, with higher numbers reflecting greater likelihood of being fired). However, when findings for the employees in these two conditions (No Leave and CWA) were combined and compared with those of equally qualified employees who took leave to care for a child with epilepsy, CWE employees were found to face both a lower likelihood of workplace rewards, $F(1, 43) = 4.06$, $P < 0.05$ (CWE $M = 3.33$), and a greater likelihood of being fired, $F(1, 43) = 6.35$, $P < 0.02$ (CWE $M = 4.45$) (see Fig. 1).

4. Discussion

Hypothetical employees who took leave to care for a child with epilepsy were found in this study to experience discrimination in the form of lower likelihood of workplace rewards and greater likelihood of being fired, even when their work performance was both actually (employee portfolio) and perceptually (participant ratings) as strong as that of their peers. They were less likely to be recommended for a promotion and raise and more likely to be recommended for job termination than were equally performing employees who had taken the same amount of leave to care for a child with asthma or for whom no leave was mentioned, with no difference in workplace outcomes observed for employees in the latter two groups.

Through our experimental approach, many of the most common reasons given by employers for the underemployment of people with epilepsy can be ruled out [4]. Inferior work performance cannot explain our findings given that the employees who were parents of children with epilepsy had a work performance history identical to that of employees in the comparison conditions. Apprehension of social discomfort due to the possibility of witnessing a seizure would also fail to account for the results given that the employees themselves were not indicated to have epilepsy. Similarly, concerns about the employee's safety and about costs to accommodate an employee who has epilepsy (e.g., insurance costs, special safety arrangements) [6] would not be applicable given that the hypothetical employees themselves did not have a history of seizures.

Other cost-related concerns, such as parents of a child with epilepsy exhibiting frequent absenteeism due to a need to care for a child with a health condition, also appear insufficient to explain the findings. First, similar concerns would seem applicable to parents who had taken leave to care for a child with asthma, particularly in light of research that has found that children with epilepsy versus asthma are not perceived to require different levels of special physical care [25]. Yet workplace outcomes for parents of children with asthma did not differ from those of employees who did not take leave. Furthermore, we found no correlation between

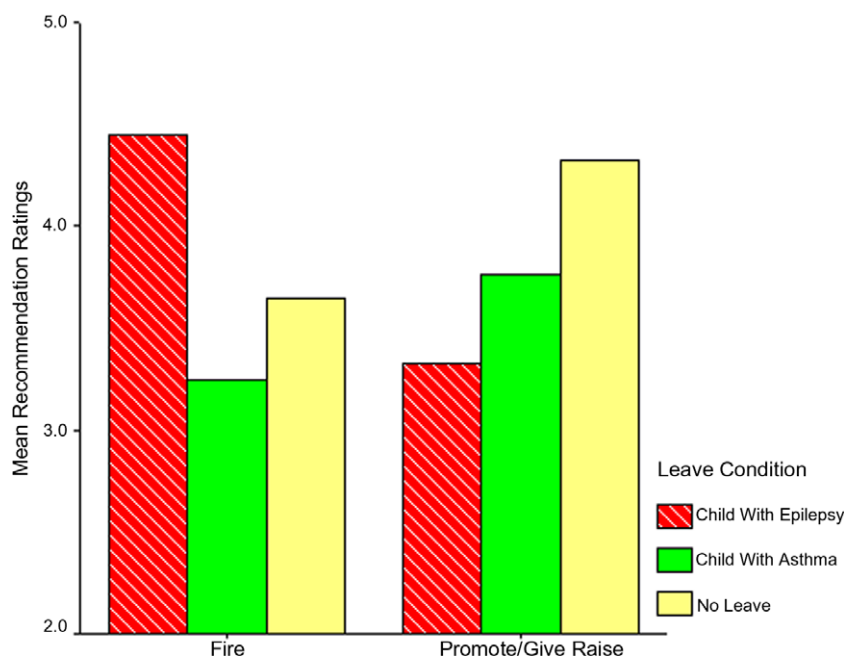


Fig. 1. Mean workplace penalties (recommendation for firing) and rewards (recommendation for promotion and raise) allocated to employees by participant "employers," as a function of leave condition. Ratings were made on a scale from 1 (strongly disagree) to 7 (strongly agree).

participants' endorsement of the APWE item "I think that a person with epilepsy constitutes a financial burden to his/her employer" and the outcomes they assigned to employees who were parents of children with epilepsy, a correlation that would be expected if concerns about employee absenteeism were driving the findings.

However, the present findings are fully consistent with a stigma/stigma by association explanation such that stigmatization accorded to people with epilepsy has become linked to individuals closely associated with that person, with this stigma negatively impacting their workplace outcomes. Our hypothetical parents of a child with epilepsy seem to have been perceived as somehow "contaminated" by their family connection to this health condition. Thus, the negative characteristics stereotypically associated with epilepsy were carried from the child to the parent. Because of these carryover effects, a person can be viewed as less than an ideal job candidate or suffer negative consequences in the workplace because of the mere association with epilepsy. Whether this effect is in part associated with fear that epilepsy is contagious or fear that it will show up later in the employee (as has been found for HIV- and mental illness-related stigma by association) remains a question for future research. Implicit measures in particular may elucidate this issue.

Given the documented importance of employment for the mental health of individuals with epilepsy [4,30], the role of stigma in limiting these individuals' workplace outcomes is of concern. Being the recipient of stigma or stigma by association, on its own, is associated with reduced mental and physical health [16,31]. Barriers to successful workplace experiences for those affected by stigma and stigma by association, and to the increments in well-being associated with these experiences, place affected individuals further at risk for reduced physical and mental health. McQuade found that lesser social support in the workplace is an additional stressor for employees who are perceived negatively based on their disease status [32]. Our sobering findings provide an opportunity to address this important problem.

4.1. Gender and the stigma/stigma by association of epilepsy

Stigma by association for hypothetical parents of children with epilepsy proved to be an equal opportunity discriminator. In contrast to prior research that has found that mothers are penalized more than fathers for taking leave to care for a child [24], fathers and mothers of children with epilepsy were equally disadvantaged, relative to their peers, in terms of both lower likelihood of workplace rewards and greater likelihood of workplace penalties. The absence of employee or employer gender effects may indicate that epilepsy-associated prejudices "trump" gender biases, no matter how strongly held, and may also be related to the stereotypic asexualization of people with disabilities. People with disabilities are often perceived as asexual and not subject to traditional gendered perceptions of men and women [33]. Our study perhaps provides evidence of asexualization by association, as well as stigma by association.

4.2. Future research

Examining epilepsy-based stigma by association with an older population and within the workplace setting itself would likely be informative. Implicit measures, in particular, might be useful tools for evaluating stigma-related negative workplace outcomes in different workplace settings, given the social desirability concerns that may impede responses concerning stigmatizing beliefs. However, we note that the present participants were attending an urban, largely commuter university in which most students work and therefore were not isolated from workplace experiences. In addition, our focus was on identifying psychological processes

that may result in lower workplace achievement of individuals who have or are associated with epilepsy. Experimental research is particularly well suited to this goal. It is notable that strong and consistent effects were obtained in this experimental study even with a sample size smaller than those normally involved in field studies, an outcome likely due to the enhanced control of the laboratory setting and consequent greater power in detecting differences. We hope that isolating the existence of this bias in the laboratory will be valuable for future field research examining workplace disadvantages faced by individuals with epilepsy and strategies to remediate these disadvantages.

5. Conclusion

Our findings depict the debilitating nature of epilepsy-based stigma in the workplace. Even when the reasons most commonly given by employers for their reluctance to hire or promote a person with epilepsy (e.g., safety concerns) were removed from the equation, epilepsy-based stigma remained. We propose that education-based organizational programs designed to address epilepsy-based workplace inequality would benefit from consideration of the mechanisms underlying the stigma and stigma by association of epilepsy.

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