

The differential effect of epilepsy labels on employer perceptions: Report of a pilot study

Malachy Bishop ^{a,*}, Donald M. Stenhoff ^a, Kelly D. Bradley ^b, Chase A. Allen ^c

^a *Special Education and Rehabilitation Counseling Department, University of Kentucky, Lexington, KY, USA*

^b *Educational Policy Studies and Evaluation Department, University of Kentucky, Lexington, KY, USA*

^c *University of Wisconsin—Madison, Madison, WI, USA*

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Abstract

A multimethod pilot study is described in which employers' and human resource professionals' perceptions of three labels used for epilepsy—epilepsy, seizure disorder, and seizure condition—were explored. Ninety-three participants were presented with a list of 10 chronic conditions or disabilities, including one of these epilepsy labels, and asked to rank-order the likelihood that a person with each condition would be hired for an assembly/production position. The participants also ranked cover letters from fictional applicants for a customer service representative position. The fictional applicants disclosed their condition using one of the three epilepsy labels. The participants then ranked which applicant would most likely be hired. Participants were also asked whether applicants should disclose their disability in a cover letter. Rasch and χ^2 analyses were used to analyze the results. Findings suggest that epilepsy was more positively perceived than the other two labels. Almost all of the participants stated that applicants should not disclose their disability in a cover letter. The results have important implications for employment seeking and disclosure practices.

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1. Introduction

Subtle differences in language and terminology can have a significant impact in shaping thoughts, attitudes, and perceptions. Whereas one label ascribed to a group of people can evoke a particular set of attitudinal and informational schemata, a different label for the same group may evoke a considerably different set. This dynamic can operate with a powerful impact in the employment application process. Cauthen et al. suggested that when a stereotype is evoked by a label, the perceiver tends to react more to the abstraction associated with the stereotype than to the referent individual [1]. In the employment application process, a known

diagnosis or disability label can bias the manner in which applicant information is received by the employer, and color employer perceptions.

Because the term *epilepsy* has a long association with stigmatizing beliefs and attitudes, we were interested in exploring whether different terms used to refer to epilepsy, including seizure condition and seizure disorder, might evoke more or less positive attitudes. The answer to this question has significant implications for job seekers with epilepsy. This article presents the results of a pilot study in which this question was explored in the context of employment, an area in which stigma and problematic stereotypes have played a significant role for persons with epilepsy.

2. Epilepsy stereotypes and stigma

In addition to being a medical diagnosis, epilepsy can be a stigmatizing social label [2]. Although regional and

* Corresponding author. Address: 220 Taylor Education Building, University of Kentucky, Lexington, KY 40506, USA. Fax: +1 859 257 3835.

E-mail address: mbishop@pop.uky.edu (M. Bishop).

national differences have been noted, stigmatizing perceptions, negative attitudes, and misperceptions about persons with epilepsy have been found to exist among groups around the world [3,4]. The stigma of epilepsy consists of deeply discrediting attributes, such as a propensity to crime and violence, sexual deviance, inheritability, and mental illness, and has led to restrictions or denials of common benefits (such as a driver's license and life insurance), and opportunities that lead to independence (such as housing and employment) [3].

Because epilepsy may be felt to be a stigmatizing and burdensome diagnosis, individuals frequently choose to conceal or not disclose it. Hopkins suggested that a person with epilepsy has to act as his or her own public relations officer, deciding how much to tell and how much to conceal [5]. Scambler described secrecy and concealment as a first-choice strategy for many people, and suggested that, frequently, disclosures were not voluntary but were provoked by clinical symptoms or other manifestations of the condition [6]. In the employment application process, personal, legal, and practical issues may impel an individual with epilepsy to disclose his or her diagnosis to an employer or co-worker.

3. Epilepsy and employment

Adults with epilepsy have consistently been found to experience higher levels of unemployment and underemployment than the general population [7–12]. Though estimates of the extent of this disparity vary, relatively lower levels of employment have been reported for more than three decades despite the fact that this period has seen improvements in clinical treatment and the enactment of legislation aimed at reducing barriers to equal employment opportunities for persons with disabilities [8,9,13–16]. Research exploring the array of clinical and psychosocial variables that may contribute to the employment problems and barriers faced by individuals with epilepsy suggests that the disparity is not due to any single factor but is, as Thorbecke and Fraser noted, “the result of a bundle of aversive factors interacting with each other in a complex fashion” [11].

Among the more frequently implicated employment barriers are employers' fears and attitudes about employing persons with epilepsy, and the fears of persons with epilepsy that they may encounter discrimination and stigmatization at work [13,14,17]. Indeed, Jacoby and associates recently suggested that for many persons with epilepsy, employer and co-worker attitudes may be the most critical determinant of their employment status and progression [13].

In the last few decades, researchers have made several efforts at understanding employers' attitudes toward people with epilepsy [e.g., 7,13,18–22]. These studies have identified issues such as fear of increased accident rates and increased insurance rates, disruption of work flow, concerns about workers' safety and comfort, and increased

expense associated with providing work-related accommodations. A general tendency on the part of employers to underestimate the prevalence of epilepsy and overestimate the frequency of seizures has also been observed [21]. These concerns continue to be prevalent despite a lack of empirical support and, in most cases, despite evidence directly contradicting them [13,20,21].

Concern on the part of persons with epilepsy about experiencing negative attitudes, stigma, and discrimination by employers and co-workers has also been consistently identified as playing a role in unemployment among persons with epilepsy [17,23,24]. For example, in a large-scale study of adults with recently diagnosed epilepsy, 70% reported that they expected to experience stigma and discrimination at work [23]. In another study conducted in the United Kingdom with people whose epilepsy was in remission, 32% of the participants reported feeling that their epilepsy made it more difficult for them than for others to get a job [24].

People with epilepsy are often hesitant to disclose their epilepsy status to employers in the employment application process [17,25,26]. Consideration of the appropriateness and necessity of disclosure may be influenced by legal, medical, social, and personal concerns. For example, in the United States, if accommodations are needed in the application process, or if work-related accommodations are necessary, then an individual with epilepsy may need to disclose her or his disability status according to the provisions for reasonable accommodation afforded under the 1990 Americans with Disabilities Act (ADA). If, however, the individual applying for employment does not require or desire accommodation and can perform the essential functions of the position without accommodation, disclosure of an invisible disability may be neither necessary nor wise. However, some people with epilepsy do elect to disclose their condition to potential employers for reasons other than legal requirements. Reasons for such disclosure may include a desire to feel one is being honest and “up front” with employers, to enable open discussion with co-workers, or to ensure that appropriate actions will be taken in the event of a seizure [17,25].

Opinions about disclosure vary considerably. In a recent survey of Epilepsy Foundation affiliates, none of the affiliates stated that they advise people with epilepsy to either disclose on applications or in initial interviews, and 19 of the 36 respondents stated that if disclosure is warranted, they advise people to disclose only after being hired [26]. In contrast, in a recent study by Jacoby et al., a majority of the employers surveyed stated that any prospective employee with active epilepsy should disclose his or her condition, preferably very early in the recruitment process, and the vast majority felt the same way about prospective employees with well-controlled seizures. As Jacoby et al. noted, “there is a clear mismatch between the position of employers, who may see non-disclosure as a breach of trust, and people with epilepsy, many of whom opt not to disclose out of fear of enacted stigma” [13].

The decision to disclose one's epilepsy in the employment application process is clearly a complex and highly individual matter, made sometimes out of necessity and sometimes out of preference. In either case, effectively disclosing and discussing one's condition and how it might be a factor in employment are critical. To this end, the present study explored two specific questions related to disclosure in the employment application process. A group of 93 human resource (HR) professionals and employers were surveyed to assess their opinions about disclosure in the application process and to determine whether the label used in disclosing one's epilepsy may have an effect on employers' perceptions of the applicant. The research questions were:

1. Does the use of different labels for epilepsy affect the likelihood that a person would be hired?
2. Do employers and HR professionals think that applicants should disclose their disability in a cover letter?

4. Methods

4.1. Procedures

The first research question was addressed using two different methods. The first involved providing participants with a job title (assembly worker in a major automotive company) and a list of 10 chronic conditions or disabilities, including in the list either "epilepsy," "seizure disorder," or "seizure condition." Participants were asked to rank from "most likely" to "least likely" the likelihood that a person who had each condition would be hired for the position. We varied the order of the presentation of the conditions and the use of the epilepsy labels such that each participant had only one of the three epilepsy labels in their list. Our purpose in this approach was to identify differences in the rankings based on epilepsy labels, with the inclusion of the other conditions providing a context for these comparisons. Although not the focus of this study, the design of this approach also allowed us to explore perceptions about hiring a person with epilepsy as compared with persons with other chronic conditions.

In the second approach, we provided a subsample of the participants with two different cover letters from fictional applicants for a position as a customer service representative. The letters were determined to be of equal quality through pilot testing conducted among the remainder of the sample. In both letters, the applicants disclosed that they had a condition that was controlled by medication and that the condition would not affect their ability to perform the job. In one letter, the applicant's condition was labeled "epilepsy," and in the other, either a "seizure disorder" or a "seizure condition." Participants ranked which applicant had a better chance of being hired. We randomly varied both the presentation of the conditions and the forms of the letters. To address the second research question, participants were also asked whether they thought applicants should disclose that they have a disability in a cover letter.

4.2. Sample

After receiving institutional review board approval, the researchers randomly selected 120 employers and HR professionals in the state of Kentucky from phone books and other publicly available databases of Kentucky employers. We attempted to incorporate employers from a range of trades and professions and of varying sizes. When possible, we specifically identified a HR professional or person responsible for hiring for contact. Selected employers/HR professionals were mailed a letter of invitation, including informed consent information, a survey questionnaire, and an addressed and postage-paid envelope. Responses were anonymous.

4.3. Rasch analysis

Rasch analysis was used to assess the comparative rankings for the first research question. The Rasch model is a one-parameter logistic model within item response theory (IRT). Rasch measurement is useful when a questionnaire or assessment is constructed to measure the degree of some property inherent in persons, in this case the willingness of a respondent to hire a candidate with the stated condition or disability [27]. Because of the complexity of Rasch analysis, an in-depth conceptual overview is not presented here, but interested readers are referred to the readings listed in the references [27–31] for further discussion of the methodology. Essentially, the Rasch model yields a comprehensive picture of the construct under measurement (in this case, *hire-ability*, or willingness to hire) and the respondents on that measure. It allows observations of respondents and items to be connected in a way that indicates the occurrence of a certain response as a probability [28]. Rasch analysis is appropriate when an individual's total score on a questionnaire is used to make inferences about the level of a latent trait inherent in that individual.

In this study, there were 10 chronic conditions or disabilities, 9 of which were ranked by all participants, and a final one, epilepsy, presented in three formats—(1) seizure disorder, (2) seizure condition, and (3) epilepsy—and ranked by three subsets of the sample. Given this format, in all, 12 items were ranked. Each chronic condition or disability can be viewed on a rank scale of 1 to 10, as assigned by each participant. A Rasch rating scale model, with the underlying dimension of hire-ability, was employed to construct a hierarchy of endorsability, or willingness to hire. The measurement model was employed largely because the model has the characteristic of sample independence, allowing for all items to be included in a single analysis (assuming the data fit the model). Measures are presented in logits (log odds units), the unit of measure used by Rasch for calibrating items and measuring persons. Logit scores can be viewed as the probability of endorsing the item, in this case the willingness of a respondent to hire a candidate with the stated condition or disability. A hierarchy is produced that results in a rank-order list with the corresponding logit measure. In addition, infit and outfit statistics are calculated. These are fit statistics, which demonstrate the general fit of the items and people within the model. Finally, an item reliability estimate, approximately equivalent to Cronbach's α , is produced.

5. Data analysis and results

5.1. Respondent characteristics

The final sample included 93 participants (response rate = 78%). The mean age of the participants was 33.3 years ($SD = 12.02$). Two-thirds of the participants were female (65.6%). Fifty-four percent had Bachelor's degrees, 24% had graduate degrees, and 22% reported education levels below a Bachelor's degree. Mean years of experience in current position was 11.8 ($SD = 8.06$). Twenty-six percent of respondents were employed by companies with fewer than 50 employees, 51% by companies with 50–199 employees, and 23% by companies with more than 200 employees. Employers from a wide range of occupations, including health care and rehabilitation, retail, banking and finance, public utilities, higher education, and employment agencies, were included.

5.2. Comparative rankings analysis

The Rasch measurement model fit well, with the item reliability being 0.95, approximately equivalent to Cronbach's α . Further, all infit and outfit statistics were well

within an acceptable range (± 2). Given that the logit scores can be viewed as the probability of endorsing the item, in this case the willingness of a respondent to hire a candidate with the stated condition or disability, a hierarchy was produced that resulted in the rank-order list with the corresponding logit measure presented in Table 1. Items with positive measures can be viewed as easy to endorse, at least in comparison to the others. Thus, cancer in remission, depression, and history of heart problems appear to be conditions that are viewed in a more positive light by potential employers. At the other end of the spectrum, the more negative a measure, the less likely a potential employer is to perceive an individual with the corresponding condition or disability as being hire-able. In this case, seizure disorder, schizophrenia, and legally blind receive the lowest rankings. Viewing Table 1, it is evident that all three labels associated with epilepsy are difficult for respondents to endorse. That being said, seizure disorder is the hardest to endorse (ranked 10 out of 12) and is meaningfully different from the other two terms, epilepsy (ranked 7) and seizure condition (ranked 8).

5.3. Application letter comparisons

χ^2 analyses suggested that there were no significant differences in the second approach to the first research question, in which 35 participants received two different letters of application and ranked them in terms of the likelihood that the applicants would be hired. Although a small majority of participants (20/35, or 57%) ranked the chances of the applicant who disclosed using the label *epilepsy* as being higher than the chances of those who used either *seizure disorder* or *seizure condition*, the difference was not statistically significant ($\chi^2 (1, N = 35) = 0.801, P = 0.500$).

Table 1
Comparative rankings of epilepsy labels ($n = 93$)

Rank order ^a	Condition	Logit measure	Mean square	
			Infit	Outfit
1	Cancer in remission	0.50	0.96	0.96
2	Depression	0.30	1.22	1.23
3	History of heart problems	0.23	0.91	0.91
4	AIDS	0.00	1.28	1.28
5	Mild mental retardation	-0.03	0.82	0.82
6	Spinal cord injury	-0.03	1.16	1.16
7	Epilepsy	-0.04	0.60	0.60
8	Seizure condition	-0.07	0.94	0.94
9	Multiple sclerosis	-0.12	0.62	0.63
10	Seizure disorder^b	-0.16	0.90	0.94
11	Schizophrenia	-0.24	1.31	1.31
12	Legally blind	-0.36	1.09	1.09
Mean (SD)		0.00 (0.23)		
Item reliability = 0.95				

^a In order from most likely to least likely to be hired.

^b Meaningful difference from *epilepsy* term.

5.4. Views on disclosure

On the question of disclosure of a disability in a cover letter, only 5 of the 93 participants (5.4%) stated that applicants should disclose that they have a disability in a cover letter. Note that in the development of the cover letters, we pilot-tested two pairs of letters because the first pair were found to be unequally ranked. During this pilot testing process, we used the term *epilepsy* in both letters as we wanted to avoid the influence of the eventual dependent variable—epilepsy labels. Thus, the results of the disclosure question are available for all the respondents, even though the rankings are not.

6. Discussion

Based on the results of this pilot study, the term *epilepsy* appears to be a more positively perceived label in the employment application process than either *seizure condition* or *seizure disorder*. *Seizure disorder* was more negatively perceived than either of the alternatives. Our expectations prior to this study were that, given the history of association that the term *epilepsy* has with stigmatizing characteristics, *seizure condition* would be the preferred term. In subsequently discussing the results with epilepsy professionals and employers, it has been suggested that, despite its sometimes stigmatizing associations, employers may have better established ideas about the meaning of *epilepsy*. On the other hand, *seizure condition* and *seizure disorder* may be less familiar, and so cause confusion with employers. The descriptor *disorder* was expected to be, and apparently is, associated with more negative connotations.

The equivocal results of the second approach to addressing the question of the impact of labels fail to clarify the question. These were based on a much smaller sample size and involve a more subtle distinction between two rather than ten labels. The approach may be fruitful in larger studies, however.

The results of the second research question provide clearer implications. The majority (approximately 95%) of HR professionals and employers in this survey do not recommend disclosing one's disability in the cover letter. Although based on a question slightly different than previous studies of this question, these results differ from the recent findings reported by Jacoby et al. in which the majority of employers preferred disclosure [13]. There are a number of possible reasons for this difference. It may be, for example, that a distinction is made between the application letter and an employment interview or other stages of the recruitment process; that employers differ in their opinions on the question internationally; that the identification of a specific position (customer service) played a role; or that the questions and methodologies of the studies differed sufficiently to create such divergent results.

Finally, the comparative analyses of the perceived likelihood of being hired compared with persons with other

chronic conditions provides an interesting, if disheartening, perspective. All of the epilepsy labels were ranked below the majority of disabilities—below cancer in remission, depression, history of heart problems, AIDS, mild mental retardation, and spinal cord injury. The rankings were based only on the descriptors provided, as they appear in Table 1, and were therefore open to considerable interpretation. The context provided for the study, auto assembly worker, may well have had something to do with the rankings, which may have reflected the well-documented concerns employers have about worker safety in a potentially dangerous environment. Further research is necessary to better understand these results.

Research on employers' attitudes toward persons with disabilities has identified that a multidimensional and complex set of underlying factors are involved. Issues such as visibility, severity, perceived responsibility, course or prognosis, risk of contagion, and familiarity have been identified as contributing factors [32–34]. Some general observations from large-scale analyses of this research include that physical disabilities are generally perceived more positively than mental and psychiatric ones, that disabilities not perceived as being related to personal responsibility are seen more positively than those that are, and that nonvisible disabilities are perceived more positively than visible ones. Overall, however, this research has produced an ambiguous and inconsistent understanding, and these observations are not consistently observed.

As Jacoby et al. recently suggested, epilepsy occupies an equivocal position in relation to these criteria [13]. In the long history of the diagnosis, numerous stigmatizing associations and characteristics have been associated with epilepsy, creating a confusion that remains prevalent. Recent evidence suggests, for example, that there remains some confusion about whether epilepsy is contagious or a mental illness [35,36]. Future studies featuring more diverse work settings and exploring the rationale by which these rankings were made would help to further elucidate employers' perceptions.

Because of the pilot nature of this study, there are several limitations involved in interpreting the results. The sample was small and geographically limited to the state of Kentucky. Previous research on employer attitudes has suggested that regional differences in employer attitudes can exist [32]. The use of rankings versus ratings limited the interpretation of the data, and a multidimensional rating approach would be more informative in future analyses.

7. Conclusion

Despite the limitations of this research, the results suggest that the question of differential responses to epilepsy labels may be an important one for further analysis. The employment application process is a complex one, and for people with epilepsy, navigating it successfully can require preparation and an informed strategy about

disclosure. If indeed the label with which one describes one's condition is among the determinants of success, then assisting persons with epilepsy to prepare for this process may include careful selection of terminology. This study suggests the possibility that the label one uses in discussing epilepsy with employers may indeed have a significant effect on employer perceptions, and further research with a larger and more diverse sample is warranted to further explore this important question.

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