

Is Ignorance Bliss? Attributions for Seizures and Consequences of those
Attributions among Participants with Psychogenic Non-epileptic Seizures

by

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ABSTRACT

Psychogenic non-epileptic seizures (PNES), is a conversion disorder thought to be linked to unresolved emotional distress. While some studies suggest that PNES patients do not attribute their somatic symptoms to severe psychological experiences (Stone, Binzer, & Sharpe, 2004; LaFrance & Barry, 2005), it is unclear what PNES patients do think causes their seizures, and the psychological consequences of those attributions. The aim of the present study was to investigate PNES patients' attributions for their seizures, and to determine how these attributions relate to stress and emotion regulation. It was hypothesized that participants who attribute their seizures to something (i.e., have an explanation for their seizures) will have lower perceived stress and less difficulty with emotion regulation than those who are unsure of the cause of their seizures. Twenty-four PNES participants completed a questionnaire assessing seizure diagnosis, characteristics of seizure impact, perceived stress, psychological symptoms, emotion regulation, attributions for seizures, and coping resources. Contrary to the hypothesis, having an explanation for seizures, rather than being “unsure” of seizure cause, was related to *greater* perceived stress. While it would seem that attributing unpredictable seizure events to a cause would lower perceived stress and emotion regulation difficulty, this study indicates that an attribution to an unknown cause may be more beneficial for the individual.

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Is Ignorance Bliss? Attributions for Seizures and Consequences of those
Attributions among Participants with Psychogenic Non-epileptic Seizures

Psychogenic non-epileptic seizures (PNES) appear similar to epilepsy in that patients experience seizure-like behaviors, such as involuntary episodes of movement, sensations, or behaviors; however, they lack the electrophysiological abnormalities present in epilepsy (LaFrance & Divinsky, 2002; Pintor & Bailles, 2005). While it is speculated that stress is a major factor in PNES (Stone, Bizner, & Sharp, 2004), causes of these unpredictable seizure-like events have stumped researchers and clinicians. The goal of the present study was to investigate PNES patients' attributions for their seizures, and to determine how these attributions relate to stress and emotion regulation difficulties in PNES patients.

In the field of stress and health, it is recognized that unresolved emotional distress may manifest somatically (Woolfolk, Allen, & Tiu, 2007). Identified as hysteria or conversion, such medically unexplained symptoms are used to identify physiological symptoms with no apparent medical explanation. These symptoms have been linked to emotional dysfunction based on theoretical grounds (LaFrance & Barry, 2005), and more recently researchers have begun to assess empirically the emotional processing of patients with these irregularities (Roberts, et al., in press).

PNES, often conceptualized as a conversion disorder, is of particular interest because of its high prevalence and severity. About 10-22% of patients

seeking treatment at epilepsy centers are those with PNES (Benbadis & Hauser, 2000; LaFrance & Devinsky, 2002). Patients with PNES are unresponsive to anticonvulsant medication and do not exhibit epileptiform activity in EEG analysis as do those with epilepsy (Frances, Baker, Appelton, 1999; LaFrance & Devinsky, 2002; Pintor & Bailles, 2005). Additionally, it is difficult to identify what PNES physically looks like, as there is no such thing as a “typical” non-epileptic seizure (Brown & Trimble, 2000). In addition to seizures, individuals with PNES are likely to suffer from mood, anxiety, and personality disorders (LaFrance & Devinsky, 2002). PNES patients are likely to have experienced family issues and severe psychiatric problems. Many PNES patients report histories of trauma and suffer from post-traumatic stress disorder (PTSD; Frances, et al., 1999). In contrast to patients with PTSD, where the trigger of their symptoms is clear (and even part of the diagnosis), PNES patients typically do not attribute their somatic symptoms to severe psychological experiences (LaFrance & Barry, 2005; Stone, Binzer, & Sharpe, 2004).

What Causes PNES?

Despite advances in treatment with psychotherapy for patients with PNES (e.g., using cognitive-behavioral therapy [CBT]; LaFrance, Rusch, & Machan, 2008), relatively little is known about the causes of PNES (Brown, Syed, Benbadis, LaFrance, & Reuber, 2011). Nevertheless, unconscious psychological processes, presence of prior trauma, somatic manifestations of psychological stress, and social or work pressures are often given by physicians to patients as causes for these unpredictable seizure-like events (Brown & Trimble, 2000;

LaFrance & Barry, 2005; LaFrance, et al., 2008). In a study of approximately 300 practitioners (75% epileptologists or neurologists), life stressors, past abuse or trauma, anxiety, and depression were causes of PNES most frequently cited to patients (LaFrance, et al., 2008). Many researchers and clinicians speculate that stress is the culprit in these psychogenic seizures, and even describe them to patients as “stress seizures” but there is no overwhelming consensus (Dr. Cornelia Drees, personal communication, March 4, 2012).

While some patients with PNES may believe physical symptoms are causing their seizures, they occur in the absence of identifiable physical causes, thus implying the contribution of psychological factors (Brown & Trimble, 2000). Mökleby and colleagues (2002) posit that PNES “may be a result of a complex interaction between psychiatric disorders, coping styles, and CNS [central nervous system] vulnerability” (p. 197). Most speculation into what causes PNES yields a psychological explanation; however, there is little understanding or consensus in the field.

PNES also has been conceptualized as a dissociative symptom (*World Health Organization*, 1992). This emphasizes the idea that seizures are caused by the failure to integrate unconscious psychological processes (Brown, et al., 2011; LaFrance & Barry, 2005). PNES patients may use dissociation as a coping mechanism to defend against the cognitive and affective components of stress or trauma (LaFrance & Barry, 2005). LaFrance and Barry (2005) note, “In the cognitive model, dissociation serves a defense function that protects the individual from overwhelming affect” (p. 365). In other words, dissociation is

supposed to serve as a defense mechanism that enables the patient to function. Therefore, dissociation may be adaptive in that the individual is not experiencing stress emotionally, but rather somatically, and for that reason, the very fact that they are under stress may be less obvious to them. Perhaps then, if individuals with PNES are introduced to the idea that psychological processes may be causing their seizures, they may be able to integrate this information (either automatically, or with the help of therapy). On one hand, this perhaps could result in a temporary increase in stress, as patients begin to experience, rather than somaticize, their emotions. On the other hand, if patients are gaining a sense that their seizure-like behaviors are stress-related and controllable (i.e., versus not knowing what causes them), lower perceived stress and less difficulty with emotion regulation may follow.

“Treatment as Usual” for PNES

When patients begin experiencing seizures (for whatever reason, epilepsy or PNES) the likely course is to seek out information from a doctor. Once epilepsy is ruled out, epileptologists or nonepileptologist neurologists often reassure the patients that the seizure-like behaviors are in fact real and that their symptoms are psychological in origin (LaFrance, et al., 2008). When patients are given a PNES diagnosis, they may be surprised that what they are experiencing is (1) not epilepsy and (2) may be psychological. In addition, “treatment as usual” consists of tapering off antiepileptic medication and directing patients to psychological/psychiatric therapy, which still does not give patients an answer to what exactly is causing seizures or how they can be treated directly (LaFrance, et

al., 2008). It may be easier to understand a physical cause versus one that is psychological.

While some studies suggest that PNES patients have poor psychological insight, and rarely attribute unpredictable somatic symptoms to past traumas or other types of stress (even though PNES is believed by the medical profession to be brought about by stressors), it is unclear what PNES patients think about what causes their seizures (LaFrance & Barry, 2005; Stone, et al., 2004). Few studies have assessed this from the patient's point of view, which may provide information for diagnosis and treatment. A certain level of insight into what is causing these seizures presumably would lead to better psychological functioning. There also may be benefits or consequences of particular attributions for seizures.

Attributions for Seizures and Psychological Consequences

One model of PNES suggests that PNES patients manifest psychological distress (e.g., experiencing sadness, or having negative thoughts about the self) somatically, rather than affectively or cognitively (LaFrance & Barry, 2005). This might suggest that individuals with PNES may be lacking the psychological insight needed to deal with or handle – or even to be aware of – psychological conflict, thus, resulting in physical manifestations in the form of seizures.

Likewise, Stone and colleagues (2004) indicate that PNES patients are less likely than patients with epilepsy to view psychological factors as relevant to their symptoms, and they maintain a more external locus of control. Perhaps then, PNES patients are more likely to attribute seizures to an external force than one that is internal. It is suggested that PNES patients believe their seizures are their

main source of stress and have a tendency to deny other life stressors (Stone, et al., 2004). While PNES patients do not attribute their seizures to psychological stress, it is interesting that they can identify feelings of anxiety and/or depression. In other words, perhaps they have some degree of psychological insight, but tend to refrain from linking seizures to psychological causes (Stone, et al., 2004).

If clinicians have a difficult time agreeing on the etiology of PNES, patients have an even more challenging time understanding the diagnosis. In a qualitative analysis into what PNES patients think of their diagnosis, Thompson, Isaac, Rowse, Tooth, and Reuber (2008) reveal that most patients hypothesized about what caused their seizures prior to receiving the diagnosis (e.g., it's not epilepsy, or it's a brain disease) and where no conclusion could be attained, the patient gave a temporary label (e.g., "blacking out," "seizures"). In addition, some participants were relieved when they received a PNES diagnosis because they obtained an answer that identified what they were going through, and were able to make sense of their symptoms. On the other hand, other participants had greater difficulty when a medically or neurologically-based diagnosis could not be provided. As the authors state, "Others appeared to struggle more to apply the diagnosis to their lives and to make their own sense of it, or could not understand the diagnosis or apply it to their lives at all, and hence rejected it" (p. 510). It is obvious and understandable that patients want an answer for their symptoms. So much so that they are willing to speculate what causes their seizures before an official diagnosis. Upon diagnosis, patients were then able to accept the label because it fit or applied to the context of their lives, or rejected the diagnosis

because it lacked relevance. Similarly, being in a “sense of limbo,” either when the cause of seizures was unknown or during medical investigation, patients reported a sense of helplessness, great distress, desperation, and did not feel able to move forward until a cause was understood. Upon diagnosis, most participants were relieved that the cause was not something more (e.g., epilepsy) and for some, allowed them to attribute the seizures to the brain’s attempt to cope with trauma and hence, understand that seizures were beyond conscious control (Thompson, et al., 2008). In conclusion, patients want an answer for their symptoms. Being able to attribute seizures to something was associated, for the most part, with relief and legitimacy. Conversely, being unable to attribute seizures to a cause or label potentially leads to negative consequences. As patients have been told by their doctors that these seizures are psychological and related to stress, it may be inferred that when patients are willing to accept a stress attribution for their seizures it relieves them of perceived stress due to uncertainty and is associated with better psychological functioning (e.g., an easier time regulating emotions). Conversely, if a PNES diagnosis does not line up with what the patient believes they are experiencing, they may reject the diagnosis and adopt a more physical explanation (even if one does not exist) as opposed to one that is psychological (in congruence with Stone, et al., 2004 and Thompson, et al., 2008) thus relating to more perceived stress and difficulties with emotion regulation.

In treatment, a certain degree of insight is needed to address emotional issues the patient may be experiencing (Brown & Trimble, 2000). If patients are able to attribute their seizures to a cause and have the emotional insight or

awareness to address the issue, a reduction in seizure frequency as well as other negative psychological symptoms may occur. In a clinical setting, insight can be empowering if it gives the patient a sense of control and enhances compliance with treatment (Hasson-Ohayon, Kravetz, Roe, David, & Weiser, 2006). However, if a patient is made to accept a diagnosis with negative connotations and stigma (e.g., schizophrenia), it can lead to a sense of helplessness and decreased motivation in improving aspects like life satisfaction (Hasson-Ohayon, et al., 2006). Moreover, having to accept a label of PNES that does not reflect one's symptoms (being told they are experiencing "stress seizures" without feeling stressed) may result in a rejection of the diagnosis because it lacked relevance (Thompson, et al. 2008). Brown and Trimble (2000) encourage clinicians to explain the close link between mind and body in an attempt to clarify why these seizures – which patients typically assume are medical/neurological in origin – appear to be psychological, even when patients do not endorse experiencing psychological stress. Although there are somewhat mixed results on the relation between insight and degree of control, the present study predicts that attributing seizures to something (having insight into the diagnosis) will be related to lower perceived stress because patients have gained a sense of control over what is going on.

These ideas are consistent with cognitive-behavioral models, which suggest that the way a person feels is contingent upon his or her views or interpretations (LaFrance & Barry, 2005). LaFrance and Barry (2005) indicate the importance of the "ABC" model of cognitive-behavioral therapy (CBT) in which

“it is not the event at point A that determines what happens at C but how the person interprets those events at point B. The interpretation might then result in psychopathology” (p. 366). The awareness or interpretation of seizures may then influence psychological functioning. Because patients are being told their seizures are psychological in nature and caused by stress, if individuals perceive this as the “answer” to their problems, attributing seizures to stress should be associated with lower perceived stress and better emotion regulation than a different attribution.

Kuyk, Stiffels, Bakvis, and Swinkles (2008) examined the effect of an inpatient treatment program (average 4.8 months) for individuals with PNES. The treatment focuses on cognitive restructuring, treatment of trauma, coping skills, and stress management, as well as individual and group therapy. Patients benefited from treatment in that there was a significant reduction in seizure frequency as well as a decrease in anxiety, depression, and dissociation, and improvement of coping abilities. They conclude that an important part of treatment is to give the “patients the opportunity to gradually get accustomed to the idea that their problem is not somatic but has a psychological origin and, at the same time, experience that their seizures are being taken seriously” (Kuyk, et al., 2008, p. 601). It may be inferred that a certain degree of insight is important for treatment and appears to alleviate negative psychological symptoms. Perhaps then, interpreting seizures as psychological in origin might result in better overall functioning.

In an assessment of the clinical profile of PNES, Ettinger, Devinsky, Weisbrot, Ramakrishna, and Goyal (1999) found that patients’ perceptions of

good health and occupational functioning were most highly correlated with decreased seizure activity 18 months after PNES diagnosis and suggested treatment. Ettinger and colleagues (1999) suggest that patients were able to find an outlet for their stress and psychological conflicts in ways other than seizures. Further, patients whose seizures decreased in frequency or subsided completely were those who believed the PNES diagnosis. It may be fitting, therefore, to say that those who attribute their seizures to some cause will have better psychological outcome than those who do not attribute their seizures to a cause.

PNES and Emotion Regulation

Difficulties with emotion regulation are present in PNES (LaFrance & Devinsky, 2002; Roberts, et al., in press). Roberts and colleagues (in press) indicate that PNES patients show difficulties, not only in self-report measures, but also in physiological measures of emotion dysregulation. Similarly, psychiatric comorbidity (frequently found in PNES) is associated with increased functional impairment (LaFrance & Devinsky, 2002; Mogleby, et al., 2002).

Physiologically, PNES is associated with lower heart rate variability, which has been associated with poor emotion regulation (Bakvis, et al., (2008). There are many ways to measure psychological functioning as it can be argued that lower perceived stress could coincide with better emotion regulation. It is important to measure self-reported emotion regulation as it can tap in to multiple dimensions of functioning (e.g., accessibility to strategies for regulation and acceptance of emotional responses; Gratz & Roemer, 2004).

Coping Strategies among PNES

Functional versus dysfunctional coping for healthy adults and individuals with PNES may be very different. Lazarus and Folkman (1987) theorize that “functional and dysfunctional coping may depend on the goodness of fit between (1) the person’s appraisal of what is happening and what is actually happening and (2) the person’s appraisal of the options for coping and his or her coping activity” (p. 159). Although problem-focused strategies often are most adaptive, an avoidance or emotion-focused strategy may be best if the situation is uncontrollable. For example, individuals with PNES tend to avoid stressful situations because they may be easily overwhelmed (hence physiological manifestations in the form of seizures) and may find confrontation of problems extremely challenging such that avoidant or emotion-focused coping would be most beneficial in reducing stress (Frances, et al., 1999).

Frances and colleagues (1999) indicate that PNES patients exhibit greater use of emotion-focused coping strategies (e.g., escape-avoidant and distancing) and are less likely to use planful-problem solving coping strategies. Frances et al. (1999) note that distancing strategies (e.g., trying to forget the seizures or to make the situation less serious) may be adaptive for stressful situations and in fact, may be the most adaptive strategy for patients who suffer from seizures. Problem-focused coping strategies may be maladaptive for those who suffer from seizures in that these strategies try to “change the unchangeable” (Frances, et al., 1999, p. 247). PNES patients may engage in more emotion-focused coping strategies because they are more adaptive than problem-focused coping strategies.

Although not empirically tested, pseudoseizures may be a form of avoidant coping based on the patient's appraisal of the event as exceedingly threatening to their well being (Lazarus & Folkman, 1987). When faced with stressful situations, pseudoseizure patients engage in escape-avoidant coping, which may maintain and increase anxiety and actually lead to a pseudoseizure. Perpetual use of avoidant coping may be effective in the present, but may have negative outcomes later, including failure to seek psychological help (Frances, et al., 1999).

Summary and Overview of Present Study

Not only do PNES patients experience more stress (perceived and objective), deny the presence of psychological stressors, and favor somatic over psychological explanations, but they are likely to engage in emotion-focused rather than problem-focused coping strategies (Frances, et al., 1999; LaFrance & Barry, 2005; Stone, et al., 2004). In conclusion, given that degree of insight or acceptance of diagnosis of PNES may be an important part of treatment for those with PNES, and attributing seizures to some cause results in improved psychological functioning in some PNES patients (Ettinger, et al., 1999; Kuyk, et al., 2008; Thompson, et al., 2008), it is hypothesized that individuals who attribute their seizures to a cause will experience better psychological functioning in terms of lower perceived stress and fewer emotion regulation difficulties than patients who do not attribute their seizures to a cause. In addition to assessing some attribution versus having an unsure attribution, the present study also extended its investigation to two attributions patients may be likely to make for

their seizures: stress and physical causes. To test these, the present study examined PNES individuals' attributions for their seizures and the relation between stress and emotion regulation.

HYPOTHESES

First, it is hypothesized that individuals with PNES who attribute their seizures to a particular cause (i.e., have an explanation for their seizures), will experience lower perceived stress (H1a) and fewer emotion regulation difficulties (H1b) than those who do not attribute their seizures to a cause (i.e., report being uncertain as to what causes their seizures).

Second, it is hypothesized that individuals with PNES who attribute their seizures to stress will experience lower perceived stress (H2a) and fewer emotion regulation difficulties (H2b) than those who do not attribute their seizures to stress.

Third, it is hypothesized that individuals with PNES who attribute their seizures to a physical cause will experience *greater* perceived stress (H3a) and more difficulties with emotion regulation (H3b) than those who do not attribute their seizures to a physical cause.

METHOD

Participants

Participants were 24 individuals with a diagnosis of PNES. Most ($n = 22$) participants were recruited from the Barrow Neurological Institute Epilepsy Monitoring Unit at St. Joseph's Hospital (Phoenix, AZ). These participants were referred to the study after being diagnosed by board-certified clinical

neurophysiologists/epileptologists using video-EEG monitoring. Video-EEG is considered the “gold standard” for diagnosing PNES, because the patient’s seizure behaviors and EEG activity are viewed simultaneously. Participants referred to the study demonstrated an absence of electroencephalographic (EEG) seizure activity when monitored using video-EEG.

The remaining 2 participants contacted the laboratory after learning about the study via a press release or word-of-mouth; previously, they had been told they have PNES by their doctor, but video-EEG confirmation was not available for the present study. Notably, analyses with and without these individuals yielded similar patterns of results.

Participants with comorbid epileptic and nonepileptic seizures, unclear diagnoses, severe sensory impairments, or severe psychiatric conditions (e.g., active psychosis, substance abuse) were not included in the study.

Most participants were European American (66.7%) females ($n = 21$, 87.5%) with an average age of 39.83 years ($SD = 11.65$, ranging from 20-63). Participants had an average of 13.40 years ($SD = 1.93$) of education, 8 (33.3%) were married, and 19 (79.2%) had at least one child. Most participants were either employed ($n = 7$, 29.4%) or on disability ($n = 6$, 20.75%). Most participants reported low or middle income ($n = 9$, 37.5% and $n = 9$, 37.5%, respectively). More than half of participants reported experiencing anxiety ($n = 16$, 66.7%) and nearly half of participants reported experiencing depression ($n = 11$, 45.8%). Additionally, over half of participants reported a previous traumatic event ($n = 16$, 69.6%).

Procedure

As part of a larger study examining emotion regulation and physiological responses in PNES, participants completed a one-hour questionnaire assessing seizure diagnosis, characteristics and impact, coping resources, perceived stress, emotion regulation, and psychiatric distress. The university's Institutional Review Board (IRB) approved this study. Participation was voluntary and all responses were confidential.

Individuals interested in the study contacted the laboratory or expressed to their physician that they would like to be contacted. These individuals were contacted by phone and were asked a set of screening questions to determine eligibility (e.g., experience PNES, age > 18). Depending on the participant's preference, the questionnaire was completed in the laboratory, mailed and completed at home, or administered online via a secure website, Survey Monkey.

Because this is part of a larger study, participants who also completed an in-lab portion were debriefed, compensated, and given a summary of previous findings about PNES at the time of the laboratory session. For those who only completed an online form of the questionnaire, upon completion, participants were given the opportunity to leave a mailing address for the purpose of compensation (\$20 Target gift card). Participants were also asked for contact information to receive a summary report of the findings. In both instances, it was made clear that contact information would only be used for the stated purpose and identifying information would not be linked to questionnaire responses.

Measures

Demographics. Participants completed questions regarding age, sex, race/ethnicity, occupation, education, income level, relationship status, health diagnoses, and seizure diagnosis.

Impact of Epilepsy Scale (IES). The IES is used to measure patients' perceptions of the impact of their seizures and their treatment on a number of aspects of their everyday life (Jacoby, Baker, Smith, Dewey, & Chadwick, 1993). Participants were asked to rate how much each aspect of their life was impacted by their seizures on a 1-4 scale (anchored by *not at all* and *a lot*). Scores on each individual item were summed into one total score. Participants were also asked the following open-ended questions: "*What happens when you have a seizure?*" and "*What do you think causes your seizures?*" (see PNES semiologies and attributions of seizures below).

Coping Resources. Participants were asked open-ended questions about their coping strategies and resources. The question of interest was "*In general, what strategies do you use to cope with stressful situations?*" Initially, the coping questionnaire was not administered to participants; therefore, coping data are available only for 13 of the 24 participants. Coping may be conceptualized as problem-focused or emotion-focused and previous studies have looked into these strategies in particular; therefore they are of interest in the present study (Frances, et al., 1999; Lazarus & Folkman, 1987).

Perceived Stress Scale (PSS). The PSS is used to measure the degree to which situations in one's life are appraised as stressful (Cohen, Kamarck, &

Mermelstein, 1983). Participants used a 5-point scale (0 = *never*, 1 = *almost never*, 2 = *sometimes*, 3 = *fairly often*, 4 = *very often*) to indicate how often they felt or thought a certain way in the past month (e.g., “*In the past month, how often did you feel you were able to control the important things in your life?*”). The present study used the 4-item short version of the PSS.

Difficulties in Emotion Regulation Scale (DERS). The DERS assesses emotion regulation difficulties and contains 6 subscales in addition to a total score in which higher scores indicate greater emotion regulation difficulties (Gratz & Roemer, 2004). Of particular interest in the present study were the total DERS score and two subscales – limited access to strategies for regulation and non-acceptance of emotional responses. Participants rate how often each item applies, using a 5-point scale: 1 = *almost never* (0-10%), 2 = *sometimes* (11-25%), 3 = *about half the time* (36-65%), 4 = *most of the time* (60-90%), 5 = *almost always* (91-100%). Items include: “*When I’m upset, my emotions feel overwhelming*” and “*When I’m upset, I feel angry with myself for feeling that way.*”

Symptom Checklist-90-Revised (SCL-90-R). The SCL-90-R is used to measure psychiatric distress (Derogatis, 1994). Participants used a 5-point scale (0 = *not at all*, 1 = *a little bit*, 2 = *moderately*, 3 = *quite a bit*, 4 = *extremely*) to rate how much discomfort they experienced during the last week due to each of the 90 problems (e.g., spells of terror or panic). This measure produces the Global Severity Index (average of all 90 items) and nine symptom subscale scores.

Quantification of Open-ended Responses

PNES semiologies. Participants' responses to the question, "*What happens when you have a seizure?*" were examined and quantified. Participants were categorized into the following semiologies: hypermotor/convulsive, hypomotor/catatonic, subjective/experiential, loss of consciousness, memory loss, stares, and other. Hypermotor/convulsive activity consists of uncontrollable shaking and jerking movements. Hypomotor/catatonic activity consists of stiffening of the body and constricted muscle movement. Subjective/experiential activity consists of participant reports of a sensation or perception (e.g., smelling or tasting or something) not perceptible to observers. Loss of consciousness or "blacking out" was explicitly stated, or there was an indication of waking up (i.e., after the seizure event). Memory loss and staring were explicitly stated. Other activity consists of chest pain, unresponsive to commands, numbness, and verbally or emotionally impacted. These categories reflect typical aspects of seizure presentation (Brown, et al., 2011).

Attributions for seizures. Participant responses to the question, "*What do you think causes your seizures?*" were examined and quantified. Participants were assigned a score of '0' (not mentioned) or '1' (mentioned) for each attribution. Of interest in the present study were attributions of *some explanation* for seizures (i.e., any explanation versus no explanation); *uncertainty* (i.e., unsure of seizure cause); *stress* (i.e., explicitly mention seizures were due to stress); and *physical* (i.e., an internal and/or external physical explanation for seizures, such as physical exertion or drug use). Other attributions assessed were: *trauma* (e.g., death of a

loved one, physical/sexual abuse, domestic violence), *other psychological* (e.g., psychological explanations and not justified by physical phenomena), and *head injury* (as explicitly stated by the participant; head injury also was categorized as “physical”).

Categorization of participant responses as described above (e.g., determining whether a response was coded as a physical attribution or not) were conducted by the investigator and independently checked by her supervisor.

Coping strategies. Participant responses to the question, “*In general, what strategies do you use to cope with stressful or emotional events?*” were examined and quantified. Participants were categorized as engaging in emotion-focused coping or problem-focused coping based on examination of these strategies in previous research (Frances, et al., 1999). Emotion-focused coping was characterized as managing emotions or feelings as opposed to dealing with the source of the problem (e.g., “retreat and withdraw” or “avoid stressful situations”). Problem-focused coping was aimed at changing or eliminating the source of stress (e.g., “reframe from negative and try to slow down”).

While the present study ultimately split coping strategies into emotion-focused and problem-focused strategies, different combinations of strategies were evaluated including escape avoidance versus relaxation/stress reduction and ignoring the problem versus take action and responses fell into the same pattern. In this case, emotion-focused and problem-focused evaluations were the most meaningful. A larger sample size may reveal stronger findings for these coping classifications.

Data Analysis

Frequencies were run to determine counts of seizure semiologies, attributions for seizures, and coping strategies.

Correlations were run to determine the relations among measures (IES, PSS, DERS, and SCL-90-R).

Independent samples t-tests were used to test the primary hypothesis that participants who made some attribution for their seizures would report lower perceived stress (per the PSS) and fewer emotion regulation difficulties (per the DERS total score and each of six subscale scores) than participants who reported being “unsure” regarding the cause of their seizures (H1).

Independent samples t-tests also were used to examine differences in PSS scores and DERS scores for participants who cited stress as an attribution for their seizures versus those who did not mention stress (H2), and participants who cited a physical cause of their seizures versus those who did not mention a physical cause (H3), with the expectation that an attribution of *stress* would be associated with lower perceived stress and fewer emotion regulation difficulties, whereas an attribution of *physical cause*, would be associated with greater perceived stress and more emotion regulation difficulties.

Additional t-test analyses also were conducted to explore relationships between endorsing each of these attributions (i.e., some explanation versus unsure; an attribution of stress versus no mention of stress; and a physical attribution versus no physical attribution) and scores on the IES and SCL-90-R.

RESULTS

In the below sections, first, participants' seizure experiences, attributions for their seizures, and coping strategies, as described in response to open-ended questions and then quantified (see Method), are reported. Second, the association between these quantified variables and other measures are reported.

As noted in the Method (see *Participants*), 22 participants were PNES patients recruited from epilepsy clinics and diagnosed using video-EEG monitoring; however, 2 participants were from the public and self-reported that they received a PNES diagnosis from their doctor. The analyses below were re-computed without these two “self-recruited” participants, and the pattern of the findings was similar (significant findings either remained significant [$p < .05$] or showed a non-significant trend [$p < .10$]).

Preliminary Analyses

Type of seizure attribution (unsure, stress, or physical) did not differ based on participant gender, marital status, or socioeconomic status (all chi squares < 5.72 , all $ps > .06$). The two primary dependent measures, PSS total and DERS total, did not differ based on participant gender ($F_s < 2.72$, $ps > .11$) or marital status ($F_s < .07$, $ps > .79$). There were differences in emotion regulation difficulties based on socioeconomic status, $F(3,20) = 4.75$, $p = .012$; low-income participants reported greater emotion regulation difficulties than middle-income participants (mean difference = 28.8, $SE = 8.2$, $p < .05$). All analyses with the DERS were conducted with and without controlling for socioeconomic status and the findings remained the same with one exception discussed below (using

analysis of covariance [ANCOVA]). There were no differences in perceived stress based on socio-economic status, $F(3,20) = 1.81, p = .177$.

Correlations among measures. There is a positive correlation between the Perceived Stress Scale (PSS) total and the Difficulties in Emotion Regulation Scale (DERS) total, $r(22) = .45, p = .03$, indicating greater perceived stress is associated with greater difficulties with emotion regulation. There is a positive correlation between the PSS total and the DERS lack of emotional clarity subscale, $r(22) = .44, p = .03$. Additionally, there is a positive correlation between the PSS total and the DERS limited access to strategies for emotion regulation, $r(22) = .41, p = .05$.

There is a significant correlation between the SCL-90-R and the DERS, $r(22) = .48, p = .03$, indicating that increased symptom severity is associated with greater difficulty with emotion regulation.

There were no significant correlations between the PSS and the IES or SCL-90-R. Also, there were no significant correlations between the DERS and the IES or SCL-90-R. See Table 1 for measure means and standard deviations.

Descriptive Results

Categorization of PNES semiologies. Nearly all patients reported experiencing seizures that are hypermotor/convulsive (e.g., “body shakes,” “jerking,” and “twitches”), and experiencing loss of awareness/memory (e.g., “black out,” and “no recollection”), with only one reporting a hypomotor/catatonic state (e.g., “stiffen up”; see Table 2).

Attributions for seizures. Most participants ($n = 17$) listed more than one cause for their seizures. Most participants gave some attribution for their seizures ($n = 19$) as opposed to an unsure attribution for their seizures ($n = 7$; e.g., “I don’t know what causes my seizures”). Other frequently cited attributions were stress ($n = 12$) and physical causes ($n = 10$). Frequency of responses by category are presented in Table 3.

Coping strategies. Ten participants reported using emotion-focused coping (e.g., “keep busy to block out what’s bothering me,” “cleaning,” and “try to convince myself that it will get better”). Three participants used problem-focused coping (e.g., “stay in the house for security,” and “working out/eating healthier”; see Table 4).

Association between Attributions for Seizures, Stress, and Emotion

Regulation Difficulties

Any explanation for seizures versus no attribution. Contrary to the hypothesis that having an explanation for seizures or attributing the seizures to something will be associated with lower perceived stress, having an explanation for seizures, rather than being “unsure” of seizure cause, was related to *greater* perceived stress as measured by the PSS (see Figure 1). Those who make some type of attribution ($M = 9.18$, $SD = 1.42$), have greater perceived stress than those who make an unsure attribution ($M = 5.86$, $SD = 2.54$), $t(22) = 4.11$, $p = .000$, $d = 1.75$. This finding remained significant when controlling for symptom severity as measured by the IES and SCL-90-R (using analysis of covariance [ANCOVA]).

Also contrary to the hypotheses, making an attribution for seizures versus being unsure of seizure cause is associated with greater difficulty with emotional acceptance, as measured by the DERS “acceptance” subscale. Those who made an attribution experienced greater difficulty accepting emotional responses ($M = 17.16$, $SD = 5.13$) than those who make an unsure attribution ($M = 11.71$, $SD = 3.73$), $t(23) = 2.51$, $p = .02$, $d = 1.07$.

Similarly, making an attribution for seizures is associated with more difficulty accessing strategies for emotion regulation, as measured by the DERS. Those who make an attribution for seizures experience more difficulty accessing strategies for regulation ($M = 22.29$, $SD = 8.37$) than those who make an unsure attribution ($M = 15.43$, $SD = 4.08$), $t(22) = 2.05$, $p = .05$, $d = .87$. However, when controlling for socioeconomic status, the finding becomes non-significant ($p = .09$). Socioeconomic status weakens the effect, but with the small sample size, including covariates may have this consequence.

Although not significant, there was a trend suggesting that those who make an attribution for their seizures have more difficulty with emotion regulation overall, as measured by the DERS total score ($M = 101.18$, $SD = 20.98$), than those who make an unsure attribution ($M = 82.86$, $SD = 16.26$), $t(22) = 2.06$, $p = .051$, $d = .88$. The other DERS subscale scores (impulse control difficulties, difficulty engaging in goal directed behavior, lack of emotional clarity, and lack of awareness of emotions) did not differ between participants who had an explanation for their seizures and those who make and unsure attribution.

Attributing seizures to stress. Surprisingly, attributing seizures to stress did not result in any significant findings. Making a stress attribution was not significantly related to perceived stress, $t(22) = -1.93, p = .066$, or emotion regulation, $t(22) = -1.27, p = .217$. For the DERS subscale scores, there was one non-significant trend revealing that those who attribute seizures to stress tend to lack emotional clarity ($M = 14.33, SD = 3.47$) more so than those who do not attribute their seizures to stress ($M = 11.25, SD = 3.93$), $t(22) = -2.04, p = .054, d = .85$.

Making a physical attribution for seizures. Results of the present study support the hypothesis that making a physical attribution for seizures is related to higher perceived stress as measured by the PSS. Those who attribute their seizures to a physical cause experience more perceived stress ($M = 9.50, SD = 1.27$) than those who do not make a physical attribution ($M = 7.29, SD = 2.52$), $t = -2.54, p = .02, d = 1.08$.

Additionally, attributing seizures to a physical cause is associated with more difficulty with emotion regulation overall as measured by the DERS. Those who make a physical attribution experience more overall difficulty with emotion regulation ($M = 106.30, SD = 18.32$) than those who do not make a physical attribution ($M = 88.36, SD = 20.37$), $t(22) = -2.22, p = .04, d = .95$.

Further, making a physical attribution is associated with more difficulty accessing strategies for regulation as measured by the DERS. Those who make a physical attribution experience more difficulty accessing strategies for regulation

($M = 24.40$, $SD = 9.47$) than those who do not make a physical attribution ($M = 17.36$, $SD = 5.26$), $t(22) = -2.33$, $p = .03$, $d = .99$.

Additional Analyses

Additional exploratory analyses were conducted to examine (1) associations between attributions for seizures and psychological symptoms (i.e., psychiatric distress per the SCL-90-R), (2) associations between attributions for seizures and participant perceptions of the impact of their seizures and their treatment (as measured by the IES), (3) whether attributing seizures to trauma was associated with perceived stress or emotion regulation difficulties, and (4) associations between attributions and coping strategies, and associations between coping strategies and measures of stress, emotion regulation, psychological symptoms, and seizure impact.

Association between attributions for seizures and psychological symptoms. There were no statistically significant associations for any of the attributions (i.e., stress, physical, some explanation, or unsure) and psychological symptoms as measured by the SCL-90-R global severity index or clinical subscales.

Associations between attributions for seizures and perceptions of seizure impact. There were no statistically significant associations for any of the attributions (i.e., stress, physical, some explanation, or unsure) and participant perceptions of the impact of their seizures and their treatment as measured by the IES total.

Attributing seizures to trauma. Attributing seizures to prior trauma did not produce any significant findings of perceived stress or emotion regulation difficulties. This was the case with and without controlling for symptoms of trauma.

Association between attributions and coping strategy. Coping strategies were gathered from 13 participants. Of these 13 participants, 12 participants gave some attribution (e.g., stress, physical, etc.) for their seizures and 1 gave an unsure attribution. Therefore, formal tests could not be conducted to compare participants who made an attribution for their seizures versus who were unsure of the cause of their seizures. Most participants who gave some attribution for their seizures engaged in emotion-focused coping ($n = 9$). The remaining participants who gave an attribution for their seizures engaged in problem-focused coping ($n = 3$). The one participant who gave an unsure attribution to their seizures engaged in emotion-focused coping. There were no participants who were unsure of the cause of their seizures and engage in problem-focused coping. In general, most participants appeared to report engaging in emotion-focused coping regardless of seizure attribution.

There were no significant correlations between strategies for coping with seizures (emotion-focused or problem-focused) and scores on the PSS, DERS, SCL-90-R, or IES.

Discussion

The goals of the present study were to (1) investigate PNES patients' attributions for their seizures, and (2) determine how these attributions relate to

perceived stress and emotion regulation difficulties. Contrary to the hypothesis that having an explanation for seizures or attributing the seizures to something will be associated with lower perceived stress, having an explanation for seizures was related to greater perceived stress. It should be noted that the present study is assessing what individuals with PNES *think* causes their seizures, not what actually causes their seizures. In fact, current evidence suggests that the only “correct” attribution a PNES patient could hold for their seizures is one in which they are unsure of what causes their seizures, because researchers and clinicians are puzzled as well.

PNES Features

As there is no such thing as a typical non-epileptic seizure, seizure characteristics were assessed. As PNES is a somewhat controversial diagnosis, there is very little consensus on what these non-epileptic events physically look like (Brown & Trimble, 2000; LaFrance & Barry, 2005; LaFrance, et al., 2008). The present study indicates that nearly all patients reported experiencing seizures that are hypermotor/convulsive (e.g., “body shakes,” “jerking,” and “twitches”) and experiencing loss of awareness/memory (e.g., “black out,” and “no recollection”), with only one reporting a hypomotor/catatonic state (e.g., “stiffen up”).

Although the sample was small, the demographics were similar to that reported in the literature in that participants were primarily female (Shen, Bowman, & Markland, 1990). Nearly half of participants reported experiencing depression and/or anxiety. This is similar to previous research that explores

comorbidity in the PNES population (LaFrance & Devinsky, 2002). Additionally, over half of participants reported a previous traumatic event. Prior trauma is common in those with PNES, but not necessary for diagnosis (Frances, et al., 1999). The present study is consistent with previous research indicating the high prevalence of previous trauma.

PNES Attributions and Consequences

Any explanation for seizures versus no attribution. Most participants listed more than one cause for their seizures. The majority of participants attributed their seizures to stress, a physical cause, or were unsure of what causes their seizures. PNES participants who attribute their seizures to a cause experience greater perceived stress than PNES participants who are unsure of what causes their seizures. This is contrary to the hypothesis that maintaining an explanation for seizures or attributing seizure events to a cause would be associated with lower perceived stress and emotion regulation difficulties.

Further indicating the benefits of an unsure attribution, there was a trend suggesting that those who have an explanation for their seizures have more difficulty with emotion regulation than those who make an unsure attribution for their seizures. Not only do PNES participants who hold an unsure attribution for seizures have less perceived stress, but they may have less difficulty with emotion regulation. Here, it may be the case that those with lower perceived stress are better able to regulate their emotions. The present study is not suggesting that seizure attributions, perceived stress, and emotion regulation are causally related constructs, as causality cannot be confirmed. It could be the case in the present

study that uncertainty of what is causing their seizures is associated with less stress and fewer emotion regulation difficulties because lower stress is leading to lower difficulties with emotion regulation. But, it could also be the reverse, that fewer difficulties with emotion regulation difficulties are related to lower perceived stress, and in turn greater acceptance regarding seizure cause being uncertain (discussed below).

While stress is commonly posited as an etiology for PNES (Stone, et al., 2004) and patients may be told that stress is what is causing their seizure-like events, it is interesting to note the potentially negative effects of making this (or any) attribution for seizures as opposed to an unsure attribution (Brown & Trimble, 2000; LaFrance & Barry, 2005; LaFrance, et al., 2008). Whereas previous literature on stress and coping more generally suggests that uncertainty is usually coupled with stress (Ettinger, et al., 1999; Hasson-Ohayon, et al., 2006) this was not the case in the present study, as uncertainty was associated with *better* psychological outcomes. Similar to previous studies of PNES, coping strategies generally considered as unfavorable, such as the use of avoidance coping, are in fact potentially useful for PNES patients (Frances, et al. 1999).

Although causality cannot be inferred from the present data, it may be the case that attributing seizures to stress leads patients to feel overwhelmed as they try to regulate their emotions (e.g., stress), thus resulting in more stress – and a vicious cycle may ensue. Therefore, holding an unsure attribution for seizures may prompt less avoidant behavior and less frustration, thus resulting in less stress

The findings of the present study are consistent with the model of CBT, but in an interesting way (LaFrance & Barry, 2005). While CBT indicates that awareness or interpretation may influence psychological functioning, as it does in the present study, here those who lack awareness or interpretation of their seizures have better psychological functioning. Perhaps accepting that seizures are occurring for unknown reasons is in fact a valid interpretation in that being unsure is enough of an explanation or answer for these unpredictable seizures to lessen perceived stress and correspond with better emotion regulation. This mirrors the medical field's interpretation of PNES that an unsure attribution is the only "correct" attribution.

Those who give an unsure attribution for their seizures have less difficulty with emotional acceptance and less difficulty accessing strategies for emotion regulation. Items on the DERS that concern emotional acceptance are similar to coping strategies in that they reflect emotion-focused coping and reject or refuse the incoming emotion. For example, one of the items, "When I am upset, I become angry at myself for feeling that way," indicates feeling a certain emotion and rejecting it by taking on another emotion. Likewise, items that concern access to strategies for emotion regulation are reflective of coping strategies (effective or ineffective). For example, "When I am upset, I believe wallowing in it is all I can do" indicates emotion-focused or avoidant coping with feelings of helplessness.

Attributing seizures to stress. Unexpectedly, attributing seizures to stress did not result in any significant findings. As stress is often given by clinicians as a cause for unexplained seizure events, it is interesting that believing stress is a

cause for seizures is not related to decreased perceived stress, emotion regulation, or psychological symptoms. Similarly, attributing seizures to prior trauma was not related to any outcome variables. In this sample, most participants were told that their seizures were in fact caused by stress, so even though participants were asked what *they* think causes their seizures, it could be that they are reporting what their doctor thinks which would not create a clear picture of seizure attribution and consequences.

In an attempt to find answers for their seizures, those who attribute seizures to something may be experiencing more stress and lapses in emotion regulation than those who simply do not know what causes their seizures. In the present study, insight into what causes these unexpected seizure events does not seem to lead to lower perceived stress or better emotion regulation as previous studies have indicated.

Making a physical attribution for seizures. Those who make a physical attribution for their seizures experience more perceived stress than those who do not make a physical attribution. Perhaps attributing seizures to some controllable (physical exertion) or uncontrollable (medical conditions) cause (both of which were included in the definition of “physical cause”), as opposed to being completely unsure of what causes seizures, leads to greater perceived stress. As noted above, if individuals are unsuccessful in regulating what they think causes their seizures, they may experience more stress. For example, previous research has indicated that trying to control a stressor appraised as uncontrollable results in more difficulties with adjustment (Forsythe & Compass, 1987).

Those who make a physical attribution for their seizures experience more difficulty with accessing strategies for regulation and more difficulty with emotion regulation overall. Here, it may mean that individuals who make a physical attribution for their seizures are holding on to the notion that something physical is causing their seizures, even though their doctors have told them that stress and psychological issues are the likely culprit. As Thompson and colleagues (2008) suggest, perhaps psychological symptoms like stress do not fully explain what the patient is experiencing and thus they are claiming a different attribution thus leading to increased perceived stress and difficulties with emotion regulation.

It seems as if patients may be hearing, “what you are experiencing may be psychological” or “we really do not know what is causing your seizures”. These two responses may have implications as to how the patient digests this information and the consequences.

Patterns of Coping

Most participants engage in emotion-focused coping, which is in line with previous research on coping with those with PNES (Frances, et al., 1999). As problem-focused coping intends to address the root of the problem, trying to change the unchangeable may be maladaptive for those with unpredictable seizure events (Frances, et al., 1999). Emotion-focused coping, therefore, may be adaptive for those with PNES as seizure frequency may decline with reduced stress and anxiety.

When exploring the benefits of a particular coping strategy (emotion-focused or problem-focused), there were no significant correlations between

strategy and health outcome (i.e., perceived stress, emotion regulation difficulties, psychological symptoms, or impact of seizure events). Most participants in this study coped with stressful situations via emotion-focused coping regardless of attribution for seizures, although the present study could not test the association between the two.

Limitations

The present study has several limitations. First, as a consequence of the small sample size, the present study lacks statistical power. Additionally, self-selection into the study limits generalizability. Second, a qualitative approach was used to understand the attributions or causes for seizures given by participants. A larger sample size and perhaps a structured clinical interview could more accurately capture participant reports. Third, a standard measure of coping was not used to assess coping strategies. An established measure of coping behavior may lead to better understanding of the coping strategies employed by individuals with PNES. Lastly, formal psychiatric diagnoses were not obtained, which would be of interest because of the comorbidity in this population. Disorders are associated with different patterns of attributions; therefore assessment of comorbidity would be useful in future research (Rief, Nanke, Emmerich, Bender, & Zech, 2004).

Of course there may be other explanations for the findings of the present study. Although perceived stress was the outcome most consistently related to the attributions for seizures, specifically an unsure attribution and a physical attribution, other factors may be responsible for seizure attributions, PSS scores,

or their associations. As comorbidity is common in this population, it may be the case that other issues (e.g., anxiety, depression, migraines) may be responsible for both higher perceived stress and particular types of attributions for seizures (LaFrance & Devinsky, 2002). For example, perhaps individuals with depression experience greater perceived stress and, through rumination, attempt to determine what causes their seizures.

Implications

What patients think causes their seizures may be useful in therapy. By assessing what patients think causes their seizures, clinicians may gain a better idea of their perceived stress level, emotion regulation capabilities, and acquire a starting point for therapeutic intervention (aimed at reducing anxiety, depression, etc.). While treatments like CBT work for those with PNES, the way in which they work for this population is not well understood. The present study suggests that perhaps it does not matter why certain treatments work or that maintenance of an attribution for seizures is necessary. The acceptance of an unsure diagnosis may be enough of an explanation to encourage lower perceived stress.

CONCLUSION

The aim of the present study was to investigate PNES patients' attributions for their seizures, and to determine how these attributions relate to stress and emotion regulation. While it was hypothesized that participants who have an explanation for their seizures will have lower perceived stress and less difficulty with emotion regulation, the present study found quite the contrary – having an explanation for seizures, rather than being “unsure” of seizure cause,

was related to *greater* perceived stress. While it would seem that attributing unpredictable seizure events to a cause would lower perceived stress, and emotion regulation difficulty, this study indicates that an unknown explanation may be more beneficial for the individual.

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APPENDIX A
MEASURE MEANS

Table 1.

Measure Means

| Measure | Mean | <i>SD</i> |
|--|-------|-----------|
| Impact of Epilepsy Scale | 2.97 | .87 |
| Perceived Stress Scale | 8.21 | 2.34 |
| Difficulties in Emotion Regulation Scale | 95.83 | 21.16 |
| Symptom Checklist-90-Revised | 1.50 | .79 |

APPENDIX B
PNES SEMIOLOGIES

Table 2.

PNES Semiologies

| Semiology | <i>n</i> ^a |
|-------------------------|-----------------------|
| Hypermotor/Convulsive | 16 |
| Hypomotor/Catatonic | 1 |
| Subjective/Experiential | 4 |
| Loss of Consciousness | 6 |
| Memory Loss | 6 |
| Stares | 3 |
| Other | 11 |

Note. ^aSome participants gave more than one seizure characteristic.

APPENDIX C

PNES ATTRIBUTIONS FOR SEIZURES

Table 3.

PNES Attributions for Seizures

| Attribution | <i>n</i> ^a |
|-------------------------------------|-----------------------|
| Any Attribution | 19 |
| Stress | 12 |
| Physical (internal and/or external) | 10 |
| Unsure | 7 |
| Trauma | 3 |
| Other Psychological | 3 |
| Head Injury | 3 |

Note. ^aSome participants gave more than one attribution.

APPENDIX D
PNES COPING STRATEGIES

Table 4.

PNES Coping Strategies

| Coping Strategy | <i>n</i> |
|-----------------|----------|
| Emotion-Focused | 10 |
| Problem-Focused | 3 |

APPENDIX E

UNSURE ATTRIBUTION AND PERCEIVED STRESS SCALE TOTAL

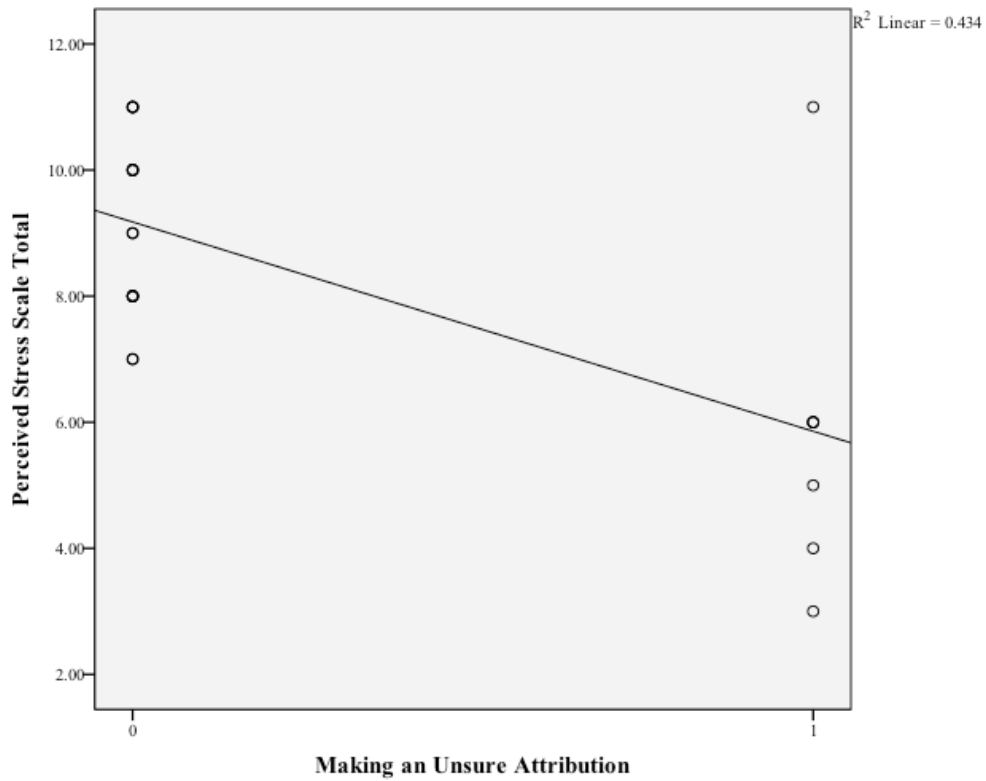


Figure 1. Association between making an unsure attribution (coded as 1) versus having some explanation for seizures (coded as 0) and Perceived Stress Scale total

APPENDIX F
INSTITUTIONAL REVIEW BOARD APPROVAL



To: Nicole Roberts
FAB

for From: Carol Johnston, Chair *sm*
Biosci IRB

Date: 01/18/2011

Committee Action: **Amendment to Approved Protocol**

Approval Date: 01/18/2011

Review Type: Expedited F12

IRB Protocol #: 0702001615

Study Title: Emotion and the Brain

Expiration Date: 03/07/2011

The amendment to the above-referenced protocol has been APPROVED following Expedited Review by the Institutional Review Board. This approval does not replace any departmental or other approvals that may be required. It is the Principal Investigator's responsibility to obtain review and continued approval of ongoing research before the expiration noted above. Please allow sufficient time for reapproval. Research activity of any sort may not continue beyond the expiration date without committee approval. Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol on the expiration date. Information collected following suspension is unapproved research and cannot be reported or published as research data. If you do not wish continued approval, please notify the Committee of the study termination.

This approval by the Biosci IRB does not replace or supersede any departmental or oversight committee review that may be required by institutional policy.

Adverse Reactions: If any untoward incidents or severe reactions should develop as a result of this study, you are required to notify the Biosci IRB immediately. If necessary a member of the IRB will be assigned to look into the matter. If the problem is serious, approval may be withdrawn pending IRB review.

Amendments: If you wish to change any aspect of this study, such as the procedures, the consent forms, or the investigators, please communicate your requested changes to the Biosci IRB. The new procedure is not to be initiated until the IRB approval has been given.

Please retain a copy of this letter with your approved protocol.

how the emotion system responds in individuals who have had or who have not had seizures or previous stressful or traumatic life experiences.

If you agree to participate in this study, your total participation will last approximately 3 hours. Approximately 150 participants will be included in this research.

Risks of Participation. If you agree to participate in this study, you may experience discomfort because you will be sitting for approximately three hours with sensors attached. You may experience discomfort because you may experience different feelings when responding to questions about your feelings and attitudes (on questionnaires or during a symptom interview), when talking about past events, or when viewing pictures that can bring up different positive, negative, and neutral feelings for some people. You may experience discomfort because you will hear bursts of noise. Finally, if you have had a seizure in the past, there is the risk you may experience a seizure during the three hours you are in the laboratory. A neurologist will be on call and will respond in the event of a seizure. We do not anticipate any other risks will result from your participation, and we do not anticipate any long-term risks. However, as with any research, there is some possibility that you may be subject to risks that have not yet been identified. During the course of the study, if the researchers find new information that would reasonably change your decision about participating, then they will provide this information to you.

Benefits of Participation. There are no direct benefits to you for participating in this research, other than intrinsic interest. You also can elect to receive a copy of the findings (presented in group form) when they become available.

Compensation. For participating in this research, you will receive monetary compensation in the amount of \$75.00. This includes completion of surveys and participation in the laboratory session. If you withdraw or are withdrawn from the study prematurely, you will receive payment for your participation at the rate of \$15/hour for any time you have spent (including any travel time incurred, up to \$75). If you complete the survey but do not participate in the laboratory portion, you will be compensated \$10. In the event of a medical emergency, '911' will be called to bring emergency medical technicians to you.

Confidentiality. All information obtained in this study is strictly confidential unless disclosure is required by law. If you learned about this study through your physician or a hospital staff member, they will *not* have access to your data. Any information collected will be used only for the purpose of this research project. Your name will not be associated with any of the information you provide, because you will be assigned an arbitrary "subject number" at the beginning of the study, and all records of your participation will be labeled only with that number. The list connecting your identity and contact information with your subject number will be stored in a locked file cabinet in a locked room in the research director's laboratory. Your name only will appear on this consent form. Your video recordings will be stored separately from your questionnaire responses and physiological data, and each will be kept in separate locked cabinets in a locked room. Only the research director and select members of the research team will have access to this office.

The results of this research study may be used in scientific reports, presentations, and publications, but the researchers will not identify you. When the findings from this study are presented, they will be presented in group form. In other words, no one will be able to identify your individual responses.

of Informed Consent conform to the Assurance given by Arizona State University to the Office for Human Research Protections to protect the rights of human subjects. I have provided (offered) the subject/participant a copy of this signed consent document.

Signature of Investigator _____ Date _____

| | |
|----------------|---------------------|
| | ASU IRB Approved |
| Sign <i>SM</i> | |
| Date | 1/16/11 - 3/16/11 |

Questionnaire Cover Letter
Arizona State University Study of Emotion and the Brain

My name is Nicole Roberts, and I am an Assistant Professor in the Division of Social and Behavioral Sciences in the New College of Interdisciplinary Arts and Sciences at Arizona State University (ASU). My students, colleagues, and I invite you to take part in a research study of emotion and the brain.

The purpose of this research is to learn more about emotion and the brain. To do this, we are studying individuals with and without different types of seizure disorders and with and without previous stressful or traumatic life experiences. (If you are someone who has not experienced a seizure, seizures are sudden involuntary movements, sensations, or behaviors.)

We are inviting your participation. This participation will involve filling out questionnaires, followed by a session in our lab where you will come in and perform several different tasks as we record your body's natural signals.

Your participation in this study is voluntary. Regarding the questionnaire part of the study, the questionnaires ask about you (e.g., your background, your health). They will take about an hour to complete. On these questionnaires, there are no right or wrong answers. Some of the questions may ask about sensitive topics. You can decline to answer any questions that make you uncomfortable by just leaving those items blank. Your name will not be written on any of these questionnaires.

If you choose not to participate or to withdraw from the study at any time, there will be no penalty. To participate, you must be at least 18 years of age. You will receive \$75 for your full participation in this study (the questionnaires and in-person research session). Should you complete the questionnaires but then not be able to come for your lab session, you will receive \$10 as compensation upon returning the completed questionnaires.

All participants will be asked to give informed consent to participate fully in this study. Should you elect to participate, your responses will remain confidential. All data will be identified with a number and the raw data and information relating numbers to participants will be kept under lock and key with very limited access or in separate password protected computers within the office of the PI. The results of this study may be used in reports, presentations, or publications but your name will not be used. Results will only be shared in aggregate form.

The only foreseeable risk from filling out the questionnaires is mild discomfort as you evaluate your own thoughts, feelings, beliefs, and symptoms.

If you have any questions concerning the research study, please call: (602) 543-4524 (our 24-hour confidential answering machine), or contact the study's research director as follows:

Nicole A. Roberts, Ph.D.
Division of Social and Behavioral Sciences

| | |
|---------------------|-------------------|
| ASU IRB Approved | |
| Sign | SM |
| Date | 11/6/11 - 3/10/11 |

Arizona State University
4701 W. Thunderbird Rd. (MC 3051)
Glendale, AZ 85306
Office Phone: (602) 543-3911
E-mail: Nicole.A.Roberts@asu.edu

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at 480-965 6788.

You can return the completed questionnaires in-person when you come for your lab session (or via mail if you are unable to come for your session), or on-line if you complete them through the confidential website.

By clicking on the button below, you are indicating that you consent to participate in the questionnaire portion of the study.

