

Towson University
Office of Graduate Studies

Predicting Quality of Life in Epilepsy: Implications for Psychological Strategies for
Seizure Management

by

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A thesis

Presented to the faculty of

Towson University

in partial fulfillment

of the requirements for the degree

Master of Arts

Department of Psychology

Towson University

Towson, Maryland 21252

May, 2012

TOWSON UNIVERSITY
OFFICE OF GRADUATE STUDIES

THESIS APPROVAL PAGE

This is to certify that the thesis prepared by Shandelle Hether entitled Predicting Quality of Life in Epilepsy: Implications for Psychological Strategies for Seizure Control has been approved by the thesis committee as satisfactorily completing the thesis requirements for the degree Master of Arts.

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ABSTRACT

Epilepsy is a neurological disorder marked by recurrent seizure activity. This disorder occurs in approximately 1% of Americans (Centers for Disease Control, 2008). Quality of life (QOL) remains to be an issue for this population. Individuals with epilepsy are approximately three times more likely to commit suicide than the general public. Despite an abundance of research investigating predictors of QOL in this population a number of limitations must be acknowledged. The following study examined research on seizure awareness, perception of control, spontaneous management strategies, depression and anxiety for their ability to predict QOL in individuals with epilepsy. A number of established measures were adapted to create a battery of assessments that can assist clinicians working with individuals with epilepsy. Results of the present study suggest this battery is a significant predictor of QOL among individuals with epilepsy. PATH analysis was used to explore the interrelationships between these psychosocial variables and QOL. Additionally, this study provides that first explicit support of a negative correlation between QOL and suicide risk. The proposed model to predict QOL is used to predict suicide risk. The results of this study provide insight into the recent development of self-management programs geared towards teaching individuals with epilepsy to use cognitive, behavioral and emotional strategies to decrease seizure activity and psychological symptoms.

Keywords: Epilepsy, quality of life, suicide, locus of control

TABLE OF CONTENTS

List of Tables	v
List of Figures	vi
Introduction	1
Statement of the Problem	10
Methods	10
Procedures	14
Results	15
Discussion	21
Appendix A – IRB Approval	24
Appendix B – Informed Consent	25
References	26
Curriculum Vitae	34

LIST OF TABLES

Table 1 Survey questions for seizure awareness	28
Table 2 Survey questions for strategy use.....	29
Table 3 Survey questions for perceived control	30

LIST OF FIGURES

Figure 1 Model Fit	31
Figure 2 Path Diagram of Proposed Model for Predicting QOLIE	32
Figure 3 Path Diagram of Proposed Model for Predicting Suicide Risk	33

INTRODUCTION

Epilepsy is a neurological disorder marked by recurrent seizure activity occurring in approximately 1% of Americans (Centers for Disease Control, 2008). A recent meta-analysis suggested that epileptics are more than three times likely to die by suicide than the general population (Bell, Gaitatzis, Bell, Johnson & Sander, 2009). This indicates that quality of life (QOL), a term that encompasses the positive and negative evaluations individuals make about their life, may be significantly reduced among these individuals. However, the relationship between QOL and suicide risk has yet to be directly studied.

Numerous assessment tools have been devised to measure QOL. These assessments, largely based on self-report, have been adapted to allow for specificity of many physical illnesses such as epilepsy. In an attempt to understand the increased suicide rate among this population, the current study examined psychosocial factors commonly used to predict QOL in individuals with epilepsy. Specifically, it focuses on four key dimensions: seizure awareness, perception of control, seizure management strategies, and psychological symptoms (i.e., depression and anxiety). However, a review of the literature indicated several problems with past use of these factors to predict QOL in individuals with epilepsy. First, research in this area tends to focus on these factors independently, without evaluating their combined effect. . However, it seems logical to suggest that these factors exert an influence on each other as well as QOL, yet to date no research has statistically explored the relationship between all of these factors and QOL. Secondly, definitions and terminology usage of these dimensions vary across researchers. This prevents meaningful comparisons of results of across studies or even specific

factors. For example, of several studies looking at “seizure control,” one study may be using the term to refer to participants’ internal or external locus of control, while another study uses the term as seizure free periods resulting from medication effects.

Few studies have systematically evaluated seizure awareness, perception of control, seizure management strategies and psychological symptoms together. The majority of research predicting QOL focuses on psychological symptoms (e.g., depression and anxiety). The most neglected of these factors include seizure awareness and seizure management strategies. Yet even when these terms are used in past literature they often do not reflect their original meaning. The present paper provides an outline of what is known about each of these psychosocial factors as they relate to potential understanding of QOL and suicide risk. Discussing each of these variables as they have been studied independently is necessary in order to develop a context for how these variables conceptually fit together into a statistical model.

Seizure Susceptibility Awareness

Three types of seizure susceptibility awareness have been studied; global, immediate, and specific. These types differ in both temporal characteristics (how close in time they are to impending seizure activity) and in specificity (the amount of detail they provide about seizure activity). Global awareness represents a participant’s, “general sense or assessment of how prone they feel with regard to having a seizure (Hether, Bruno, Johnson & Galupo, n.d.).” This differs from an immediate sense of awareness or aura in which seizure activity is followed within seconds or minutes of perceiving a familiar feeling or sensation (Snyder & Nussbaum, 1998). Specific types of awareness refer to an individual’s knowledge of seizure precipitants which could reflect various

personal states that usually precede seizure activity. It seems that the majority of individuals with epilepsy have some awareness of seizure precipitants with common examples including feeling tired, overexcited or having consumed alcohol (Antebi & Bird, 1993; Spector, Cull & Goldstein, 2001).

Perception of Control

Research investigating internal locus of control or the extent to which an individual attributes the outcome of events to their behavior or personal characteristics (Rotter, 1990) has existed since the late 1950's. In the epilepsy literature locus of control commonly refers to an epileptic individual's ability to prevent or lessen impending seizure activity. In fact, nearly half of individuals with epilepsy have been found to endorse some amount of control over terminating seizure activity (Antebi & Bird, 1993). It has been predicted that an internal locus of control would be associated with greater awareness of seizure susceptibility. For example, Spector, Cull and Goldstein (2001) found that individuals with higher levels of control were more likely to be associated with the presentation of an aura. In a sample of 58 participants who were classified as high controllers, approximately 42 percent of participants reported having an aura compared to 30 percent of the 21 participants classified as low controllers (Spector, Goldstein, Cull & Fenwick, 1994).

An individual's level of awareness of impending seizure activity likely affects QOL through the mechanism of perceived control. For instance, having foreknowledge of one's next seizure allows an individual time to prepare for the effects of the seizure or elicit help for others nearby, thus increasing the perception of control over the situation. Conversely, limited awareness of seizure susceptibility may make an individual feel as if

the seizures are unpredictable and that he/she has no control over the situation. The chronic effect of this lack of control may represent learned helplessness, thereby increasing an individual's depression and decreasing QOL. The notion that an individual's awareness of seizure risk is related to his/her perception of control over seizure activity has previously been suggested (Spector, Goldstein, Cull & Fenwick, 1994). However, the research evaluating this relationship is limited. Perception of control has only recently been examined for its involvement in the QOL of individuals with physical illness such as epilepsy (Velissaris et al., 2007; Antebi & Bird, 1993; Salgado & Cendes, 2009; Spector, Cull & Goldstein, 2001; Asadi-Pooya et al., 2007). Perception of control over seizure activity has been found to correlate with QOL such that the more control individual's believe they have over the onset or severity of seizure activity the greater their QOL (Velissaris et al., 2007; Salgado & Cendes, 2009). However the degree to which QOL varies by different degrees of seizure awareness is not fully understood. It seems logical that greater seizure awareness would lead to greater perceived control and thus greater QOL, yet this has not been explored. It is also possible that some individuals with high levels of seizure awareness have little perceived control. If this is to be found it might be possible to assist these individuals in fostering a sense of control over their seizure activity and ultimately increase their QOL. In order to address this it is important to look at individuals who use a number of psychological seizure management strategies to maintain a sense of control over their illness.

Seizure Management Strategies

Seizure management strategies typically refer to any unprompted cognitive, behavioral or emotional strategy used to manage the onset or severity of seizure activity,

however nowhere in the current literature is this definition clearly demarcated. This lack of definition invariably contributes to the miscommunication of researchers and the misunderstanding of how these strategies could be used to understand and even predict QOL.

Previous qualitative work has examined such seizure management strategies used by individuals with epilepsy (Hether, Bruno, Johnson & Galupo, n.d.). Semi-structured interviews were conducted with participants ($N=9$) referred from an Epilepsy Foundation service. Thematic analysis of interview transcripts revealed that the types of spontaneous strategies used were dependent on whether participants had a global or an immediate (aura) sense of seizure susceptibility. Individuals who had a global or diffuse sense of seizure susceptibility tended to use more behavioral strategies to abort seizure activity (e.g., sitting down or not climbing a ladder) while individuals with an immediate sense or aura presentation used cognitive strategies more (Hether, Bruno, Johnson, & Galupo, in progress).

Velissaris et al. (2007) conducted interviews ($N=90$) to examine potential pathways of psychological adjustment in individuals recently diagnosed with a seizure disorder and to examine how participants used strategies to maintain perceived control. This research assessed participants at two time points; one month after their first seizure and then again two months later. One month after diagnosis, the researchers found two main pathways of adjustment. The first pathway was one in which individuals with less perceived control over their seizures engaged in more behavioral and emotional strategies to increase their perception of control. Individuals here experienced significant psychological symptoms such as depression and anxiety. Individuals in the second

pathway started out with relatively greater perceived control and engaged in less behavioral and emotional strategies. At three months after diagnosis depression and anxiety scores for individuals on the first path of adjustment (less control) improved and individuals on the second path of adjustment (more control) remained low.

The research by Velissaris et al. (2007) is important in providing insight into the general use of strategies to exert seizure control especially for individuals in different adjustment periods. However, it should be used cautiously when trying to make claims about the relationship of awareness, strategies and QOL in individuals with epilepsy. For example, in their research the term “strategies” was used to refer to coping strategies and was only assessed at one and three months after the onset of seizure activity. Assessing individuals even three months following seizure onset may not reveal the most successful coping strategies used by individuals with epilepsy as they are still probably in an inchoate stage. Furthermore, this research did not evaluate participants’ levels of seizure susceptibility awareness. One possible explanation for the finding of decreased depression and anxiety scores in individuals who started out with less perceived control is that their awareness of their seizure susceptibility increased. Finally, the extent to which this research provides meaningful information on QOL is limited as their QOL measure was not administered in its entirety (Velissaris et al., 2007).

Another study, similar in aim, conducted by Spector, Cull and Goldstein (2001) used a different approach of assessing these strategies. In this study 100 adult participants with epilepsy were provided with Rosenbaum’s (1980) Self-Control Schedule (SCS) to evaluate the general daily strategies they use to cope and self-regulate. Participants were also categorized as having either high or low perception of control. This study found

participants more likely to be categorized as high controllers. Additionally, correlations were computed to test the association of anxiety, depression, and control strategies among participants with high or low perceived control. Their results showed no significant differences between the two groups in terms of psychological symptoms or control strategies.

These nonsignificant findings may be related to the researchers' methods of categorizing participants into high and low controllers and their use of the SCS. In this study a participant's degree of control was dichotomized as either high or low based on the responses of six interview questions. High controllers were said to have answered positively on "many" questions measuring control while the low controllers answered negatively to "many" questions. Latent class analysis was used to distinguish between high and low controllers. Responses with a probability $> .8$ or $< .2$ were classified as belonging to the high control group or the low control group, respectively. This type of analysis has not reportedly been used in any other study measuring control. Interestingly though, when participants with high scores on a separate internal locus of control measure were examined regardless of their high or low control status they were found to have lower depression scores and greater scores of control strategy use than participants who had lower scores on the internal locus of control measure.

This Self-Control Schedule (SCS) was also less than ideal at studying perceived control of seizure activity for a number of reasons. Chief among these reasons is that it is not specific to an individual's response to seizure activity. For example item number 14 reads "I spend too much money." While this item would be helpful in measuring a person's general self-control, it does little to provide information regarding how an

individual exerts control over their seizure activity. Strategies for managing seizure activity as it is occurring may be very different than the basic coping or self regulating strategies people use in their everyday life.

Depression and Anxiety

Depression and anxiety have frequently been found to co-occur in individuals with epilepsy. Although the exact rate is uncertain, depression seems to occur in approximately 45% of individuals with frequent seizure activity and in 5% of individuals whose epilepsy is managed by medication and or surgery (Kanner, 2003; Salgado & Cendes, 2009; Velissaris et al., 2007; Asadi-Pooya et al., 2007). Increased rates of depression and anxiety have been associated with lower rates of perceived control (Pedroso de Souza & Salgado, 2006; Velissaris et al., 2007) and lower ratings of QOL (Tracy et al., 2007).

Of 151 participants with epilepsy given a 31-item measure of QOL in epilepsy (QOLIE-31) and the Beck Depression Inventory (BDI) Salgado & Cendes (2009) found a significant relationship between depression, anxiety, and QOL. Kwan et al. (2009) reported a similar finding. In this study 247 participants with epilepsy, referred from an outpatient service, completed surveys which included the Hospital Anxiety and Depression Scale (HADS) and the QOLIE-31. They found scores from the HADS to be correlated with scores on the QOLIE-31 measure. In particular they found that the HADS depression scale accounted for 29.6 percent of the variance in QOLIE-31 score and the HADS anxiety scale accounted for 55.7 percent of the variance in QOLIE-31 score.

Recently, it has been suggested that epileptic individuals with both anxiety and sub-threshold depression are associated with poorer QOL than individuals who have

anxiety or depression alone (Kanner, Barry, Gilliam, Hermann & Meador, 2010). In their study, Kanner, Barry, Gilliam, Hermann & Meador (2010) conducted structured clinical interviews to identify DSM -IV axis I disorders in 188 participants with epilepsy. The MINI International Neuropsychiatric Inventory, the BDI-II and a QOL in epilepsy 89 item measure were also used. This study found that participants' scores of depression that were in the subclinical range had decreased levels of QOL than individuals without depression. Additionally, participants who also scored in the clinical range for an anxiety disorder were found to have lower scores of QOL than participants who only scored in the subclinical range for depression.

In a recent population based study in Denmark, the rate of completed suicides was three times higher for individuals with epilepsy compared to controls. This rate was made even higher when individuals with epilepsy had comorbid depression and anxiety or during the first few months after diagnosis with a seizure disorder (Christensen et al., 2007).

Thus far it has been demonstrated in the literature that seizure susceptibility awareness has been associated with perception of control which is related to seizure management strategies which in turn is also related to depression and anxiety in individuals with epilepsy. The primary objective of the current study is to systematically evaluate the power of each of the above psychosocial factors to predict QOL in individuals with epilepsy. Toward this aim, the current study established a battery of measures to assess each factor. Finally, the current research examines the extent to which these same psychosocial factors can be used to predict suicide risk among this population and aid in the easier and earlier identification of individuals at risk for suicide.

STATEMENT OF THE PROBLEM

As previously indicated there is much room for the literature on QOL in epilepsy to be improved. Current research varies in the definitions and assessment methods of relevant predictor variable, making it difficult to understand and compare research findings. The current study uses a modified battery of self-report assessments to ascertain participants' level of seizure awareness, perception of control, seizure management strategies, and psychological symptoms to clarify their roles in predicting QOL. Additionally, the relationship between these factors and suicide risk is examined. Greater understanding of this relationship may assist clinicians in the early identification of individuals at greater risk for suicide as well as provide insight into new developments in self-management programs geared at increasing QOL in this population.

Specifically, the present study seeks to address the following hypotheses:

1. Participants' scores of seizure awareness, perception of control, spontaneous strategies to manage seizure activity, depression and anxiety will be predictive of QOL scores in individuals with epilepsy.
2. Greater use of spontaneous strategies to abort seizure activity will be positively correlated with increased scores of QOL and decreased scores of suicide risk compared to participants' who report less use of spontaneous strategies.
3. Participant's level of perceived control (mediator) will explain the relationship between seizure awareness and strategy use.

METHODS

Participants

Participants were recruited from local universities, online-forums, and local support groups derived from the Abilities Network which is a division of the Epilepsy Foundation of America. Inclusion criteria for participants were as follows. Participants must have been at least 18 years of age and able to provide consent to take part in the study. Participants must have also received a diagnosis of epilepsy by a qualified professional prior to their involvement in the current study. Participation in the study was completely voluntary and participants were able to withdrawal from the study at any time. At the conclusion of the study, participants could enter a lottery to win one of three twenty-five dollar Visa gift cards.

A total of 142 adults with epilepsy participated in the study. Participant's age ranged from 18-60 ($M=32.5$, $SD= 11.3$). Approximately 64% of participants identified as females and 33% identified as males. Eighty one percent of participants identified as Caucasian, 2.1% Hispanic, 3.5% African American, 7% Asian, and .7% Native American. Approximately 17% of participants indicated a high school diploma as their highest completed level of education while another 17% were currently attending college, 7% held an Associate's degree, 22.5% held a Bachelor's degree, and 12.7% had either completed or were currently working towards a post graduate degree. Forty seven percent of participants were currently employed. The number of anti epileptic drugs (AED) currently taken by participant's varied from zero to more than five with the average of participants taking 1.72 AED's, $SD = 1.11$. Eighteen percent of participants endorsed having had surgery to correct or lessen the severity of their epilepsy.

Measures

Seizure Awareness Scale (SAS)

The SAS was developed for this study to measure the level of seizure susceptibility awareness in individuals with epilepsy. The SAS consists of a total of 8 statements in which individuals are instructed to rate their level of agreement on a 4-point Likert scale. Thus total scores ranged from 0 to 32. Higher scores indicate greater participant seizure susceptibility awareness.

Perception of Seizure Control Scale

This 6-item scale was designed for the present study to measure the degree of control an individual with epilepsy perceives to have over seizure activity (internal locus of control). Four items were adapted from Form C of the Multidimensional Health Locus of Control (MHLC) scale to allow greater specification for individuals with epilepsy and to create a briefer measure of control. Items are rated according to a 4-point Likert scale yielding a score range of 0-24 with higher scores indicating a greater internal locus of control. The four items adapted from the MHLC were chosen based on relevance and previously demonstrated reliability and validity.

Cognitive, Behavior & Emotional Strategies for Seizure Control (CBES-SC) Scale

The CBES-SC scale has been adapted from the Emotional Regulation Questionnaire (ERQ; Gross & John, 2003) and the Cognitive, Emotion Regulation Questionnaire (CERQ; Garnefski, Kraaij & Spinhoven, 2001) to extend its application to types of strategies used by individuals with epilepsy to control seizure activity. Both the ERQ and the CERQ have been found to have good psychometric properties with the CERQ showing Cronbach's alpha reliability coefficient between .68 and most often above .80 (Garnefski & Kraaij, 2007) and above .73 for ERQ's reappraisal and suppression scales and a test-retest reliability of .69 (Gross & John, 2003).

The CBES-SC consists of 9 statements that make up three independent subscales. These subscales include cognitive refocusing, emotional refocusing, and behavioral refocusing-planning. Each scale is comprised of three items and is measured on a 4-point Likert scale. Scores on each subscale range from 0- 12, with higher scores, indicating higher use of that particular strategy. A combined score of all three subscales, range 0-36, can be used to indicate overall use of strategies to manage seizure activity. Higher overall scores, represent higher use of spontaneous strategies.

Quality of Life in Epilepsy-31 (QOLIE-31)

The QOLIE-31 is a brief, 31-item measure of quality of life that encompasses many factor specific to those who have epilepsy. These factors include rating of seizure worry, concerns of anti-epileptic medication effects, and various levels of functioning. Scores on the QOLIE-31 range from 0-100 with higher scores representing better QOL. The QOLIE-31 has been demonstrated to be reliable with Cronbach's alpha coefficients ranging from .77 to .85 and test-retest reliability to be between .64 and .85 (Cramer et al., 1998). This measure has been adapted from its original paper-pencil form with permission to allow for delivery with an internet based survey.

Beck Depression Inventory- II (BDI-II) & Beck Anxiety Inventory (BAI)

The BDI-II and the BAI are widely used and well established measures of depression and anxiety. Both are 21-item self report measures that use a 4-point Likert scale and produce scores that range between 0 and 63. In the BDI-II scores of 10-13 indicate minimal depression, 14-19 mild depression, 20-28 moderate depression and scores above 20 indicate severe depression (Beck, Steer & Brown, 1996). For the BAI

scores 0-7 represent minimal anxiety, 8-15 mild anxiety, 16-25 moderate anxiety, and 26 or greater as severe anxiety (Beck, Epstein, Brown & Steer, 1988).

Seizure Risk Assessment

The SAD-PERSONS suicide assessment developed by Patterson et al., (1983) measures ten most common risk factors for suicide; sex, age, depression, prior history, ethanol abuse; relational thinking loss, support system loss, organized plan, no significant other and sickness. This measure was selected for use in this study because it is frequently used by clinicians in hospital settings – where individuals with epilepsy would typically present to after seizure activity and for its ability to be delivered in an electronic format. Individuals whose responses are consistent with meeting a risk factor receive a score of one on that factor. Guidelines for hospital staff are included in interpreting scores. Scores range from 0 to 10 with scores between 0-2 to be at no real risk at capable of discharge, 3-4 some risk but discharge at check on frequently, 5-6 considerable risk should be admitted, 7-10 definite risk for suicide hospitalization strongly recommended. The validity of this scale understandably lacks an exact estimation as this would require hospital staff to discharge individuals assumed to be at risk and then to follow them to determine if they died by suicide.

Procedures

Individuals with epilepsy were invited to complete an internet based survey regarding their level of seizure awareness and the degree to which they engage in cognitive, behavioral or emotional strategies to modify their seizure activity. All surveys were anonymous and can be accessed through a secure server. Participants were also instructed to indicate their degree of awareness as well as use and effectiveness of seizure

control strategies by rating their level of agreement with twelve statements on a five-point Likert scale. Data were analyzed using SPSS Statistics version 19 software and Amos 5 graphics.

RESULTS

Preliminary Reliability Analyses of SAS, CBES-SC & Perception of Seizure Control Scales

Preliminary analysis focused on establishing reliability of the following new measures developed for this study; Seizure Awareness Scale, Cognitive Behavior & Emotional Strategies for Seizure Control and Perception of Seizure Control Scale. Exact survey items can be found on Tables 1-3. Of the original eight items on the Seizure Awareness scale, one item "*my seizures occur out of the blue (i.e., without warning)*" was excluded from analyses due to low internal consistency. The final seven item scale yielded a Cronbach's alpha of .82 suggesting the scale is a reliable measure. A Cronbach's alpha of .84 was achieved for the Cognitive, Behavior & Emotional Strategies for Seizure Control (CBES-SC) Scale indicating good reliability. The Perception of Seizure Control Scale resulted in a Cronbach's alpha of .67 which is slightly lower than the previous scales but still acceptable according to George and Mallory (2003). As a result of this, the six items of the scale were entered into a factor analysis with Varimax rotation. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .719 indicating that the scale was adequate for factor analysis. Three scale items representing perception of internal control loaded on one factor while the remaining three items corresponding to perception of external seizure control loaded on the second factor. Combined, these two factors accounted for 57.69% of the variance.

Awareness, Perception of Control, Strategy, Depression, & Anxiety predict QOLIE scores

The degree to which participants' seizure awareness, perception of control, strategy use, depression and anxiety scores predicted QOL in individuals with epilepsy was tested using multiple hierarchical regression. Predictor variables were entered into the model in two blocks regressed against the dependent variable of QOL. The first block of predictor variables included seizure awareness, perceptions of control and overall strategy use. The second block of variables included BDI-II and BAI scores. The first block of predictors (awareness, perception of control and strategy use) by itself did not yield a significant regression equation, $F(3,104) = 2.544, p = .06, R^2 = .068$. This result suggests that awareness, control and strategy use alone account for 6.8% of the variance in participants QOLIE-31 scores. Consistent with the first hypothesis, a significant regression equation, $F(5,102) = 28.395, p < .000$, with an R^2 of .582 was found for the overall model (Figure 1). The F change had significantly increased ($p < .001$) when BDI and BAI were entered to the model. Together, this model accounted for 58.2% of the variance in participants QOLIE-31 scores.

Spontaneous Strategies to Abort Seizures Correlated with Suicide Risk but not QOL

Pearson's r correlation was used to examine the association between participant strategy use and suicide risk. An unexpected weak significant positive correlation was obtained for the second hypothesis, ($r(142) = .228, p = .003$), indicating that higher use of strategies were associated with higher suicide risk. Subsequent exploratory path analysis

later provided additional insight into the mechanisms by which strategy was associated with suicide risk. This mechanism, as described later is depression and anxiety.

The relationship between participants' strategy use and quality of life was assessed by using Pearson's correlation coefficient. A non significant correlation was found ($r(107) = .091, p = .174$). This result is likely related to 1.) a substantial number of participants that have had surgery to correct their epilepsy which would render their responses inapplicable or 2.) an a priori hypothesis that strategy use would vary by an individual's level of awareness and perception of control.

To address the first problem, the correlation between strategy and QOLIE was reanalyzed excluding participants who endorsed having surgery to ameliorate their epilepsy. The correlation between strategy use and QOL was significantly higher ($r(90) = .159, p = .068$). Regarding the second issue, it was hypothesized that strategy use varied by participants level of awareness of seizure susceptibility, a relationship that is mediated by perception of control. A Pearson's correlation coefficient was calculated to determine the relationship between awareness and strategy use. A significant and moderate positive correlation was found ($r(121) = .364, p = .000$). The more participants were aware of impending seizure activity, the higher their use of strategies to manage seizure activity.

Perceived Control Mediates the Relationship between Seizure Awareness & Strategy Use

Sobel's test of mediation was used to test whether participants' level of perceived control mediated the relationship between seizure awareness and strategy use. A significant Sobel's value was found, Sobel = 2.52, $p = .01$. When participants' awareness and control predicted strategy use Pearson's r increased to .514. The percentage of the

total effects mediated was 27.2%. The ratio of the indirect to direct effect was .37. This suggests that nearly 30% of the relationship between awareness and strategy varies as a result of perceived control. Therefore an individual with high level of awareness of seizure activity can use strategies to manage their seizure. However, whether they choose to engage in strategies is in part related to whether a participant believes they have some control to manage seizure activity.

PATH Analysis Reveals Interrelationships between Psychosocial Variables and QOL

Exploratory Analyses focused on the interrelationship between participant's awareness, perception of control, strategy use, BDI-II scores and BAI scores and QOLIE-31 was tested using path analysis with AMOS 5 for SPSS (for a path diagram see Figure 2). Path analysis resulted in a Comparative Fit Index (CFI) of .778 and a Normed Fit Index (NFI) of .774. These values range from 0 to 1 with values closer to 1 considered to indicate that the proposed path diagram is a good fit. Maximum Likelihood estimates indicate that as participant's level of awareness of seizure susceptibility increases by 1 point on the awareness scale, total strategy use increases by .535; as awareness increases by 1.0 on the awareness scale participant's level of perceived control also increases by .523; when the relationship between awareness is mediated by control then strategy use increases .795 per point of seizure awareness on the awareness scale; as strategy use increases per point on the strategy scale participant's BDI-II scores *increased* .554 points and BAI scores *increased* by .584; as strategy use increased per point on the strategy scale participant's QOLIE-31 increased by 2.12; as participant's depression scores increased per point on the BDI-II their QOLIE-31 scores decreased by .430; finally as participant's

anxiety increased per point on the BAI scale participants QOLIE-31 scores decreased by .231. Squared multiple correlations and standardized regression coefficients are listed in the figure below.

Negative Correlation between QOL and Suicide Risk

After establishing that these psychosocial variables are significant predictors of QOL, the next logical step was to establish a relationship between QOL and suicide risk. This relationship is needed to explore whether the proposed model of psychosocial variables could also be used to predict suicide risk. Pearson's *R* correlations were calculated and indicated a significant negative correlation between QOLIE-31 scores and suicide risk, $r(109) = -.542$, $p = .0001$. As an individual's QOL decreases, their suicide risk increases.

Proposed Model Predicts Suicide Risk, but Comparisons between Models Show that Psychosocial Variables to Predict QOL Yield Better Fit

The extent to which the proposed model could predict participants' scores on the SADPERSONAS measure, or suicide risk was examined using linear regression. Path analysis was also used to explore the relationship between the predicted model and suicide risk (see Figure 3). This analysis was then compared to the model and path analysis of the original model predicting QOLIE-31. These models were compared to each other using the Akaike information criterion (AIC) to determine whether or not they yielded similar model fits. Models with smaller AIC's indicate a better model fit.

A significant regression equation was found such that participants' awareness, perceived control, strategy use, BDI, BAI, and QOLIE-31 scores predicted a participant's suicide risk using the SADPERSONAS scale ($F(6,101) = 15.282$, $p = .001$, $R^2 = .476$.

According to path analysis, the Comparative Fit Index (CFI) was .650 and the Normed Fit Index (NFI) was .646. Maximum Likelihood estimates indicate that as participant's level of awareness of seizure susceptibility increases by 1 point on the awareness scale, total strategy use increases by .535; as awareness increases by 1.0 on the awareness scale participant's level of perceived control also increases by .523; when the relationship between awareness is mediated by control, then strategy use increases .795 per point of seizure awareness on the awareness scale; as strategy use increases per point on the strategy scale participant's BDI-II scores *increased* .554 points and BAI scores *increased* by .584; as participant's depression scores increase one point on the BDI-II their QOLIE-31 score decreases by .430; as anxiety increases per point on the BAI QOLIE-31 decreases .231; and when participant's QOLIE-31 scores increase by one point their suicide risk on the SADPERSONAS scale decreases by .002 or .03 standard deviations above zero. A number of explanations could account for the unexpected finding that strategy use was related to increases in depression and anxiety. For example, it is possible that people with higher depression and anxiety use more strategies than people with lower depression and anxiety. It is also possible that strategies were effective in reducing individual's depression and anxiety but participants already had higher base rates of depression and anxiety. The current research only assessed participants at one time point, thus was unable to determine the accuracy of this base-line hypothesis.

The AIC of the model predicting SADPERSONAS is 258.036 which is greater than the AIC of the original model predicting QOLIE-31, AIC =153.085. This suggests that the original model predicting QOLIE-31 is a better fit than the model predicting SADPERSONAS although regression shows that both models are significant.

DISCUSSION

Epilepsy is a chronic neurological illness that has effects on an individual's psychological functioning. Individuals with epilepsy have higher rates of comorbid depression, anxiety, history of suicide attempts and lower ratings of QOL. Although a number of variables have been explored in the literature spanning biomedical, psychological and social domains, the current study chose to focus on psychosocial variables. The focus on psychosocial variables is needed to help identify individuals with low QOL, who may be at a higher rate of suicide.

The current study offers several contributions to research in the area of psychological seizure management. First, new reliable and valid measures have been developed for; 1) seizure awareness; 2) cognitive, behavioral and emotional strategies for seizure control; and 3) perception of seizure control. These new scales when accompanied by the BDI-II, the BAI and QOLIE-31 create a battery of tests that predict the QOL of an individual with epilepsy. Based on the statistical model outlined in the present study, this battery is a significant predictor of QOL in individuals with epilepsy. This represents the first theoretically driven statistical model to use spontaneous strategies and seizure awareness, control, and psychological symptoms to predict QOL. This model accounted for a significant ($r^2=.582$) amount of variance in QOL. Furthermore it is the first of its kind to take this information and create a path analysis to explain the interrelationships between these predictor variables and QOL. These results may aid future clinicians working with individuals with epilepsy by allowing earlier identification of individuals with low QOL who may be at an increased risk for suicide.

Additionally, greater understanding between the relationships of these psychosocial variables and QOL provides insight for the effectiveness of future strategy training modules for individuals with epilepsy. Such training modules have previously been hypothesized to work by increasing an individual's perception of control over seizure activity thereby increasing their QOL (Pramuka et al., 2007; Westerhuis et al., 2011; Antebi & Bird, 1993; Fraser et al., 2011).

Results of the current study suggest that such training modules may not be as effective for individuals as hoped. Although there is a positive correlation between awareness of seizure activity and strategy use, strategy use is actually associated with increases in depression and anxiety scores. This finding is especially interesting and unexpected as it goes against the very assertion that training programs to teach individuals with epilepsy to use strategies would decrease these symptoms. After the direction of the relationship was determined using PATH analysis, Pearson *R* correlation was calculated to determine the strength of the relationship between strategy use and depression and strategy use and anxiety. A moderate significant association was found for strategy use and depression ($r(119) = .297$, $p = .001$) as well as strategy use and anxiety $r(119) = .440$, $p = .000$).

A number of limitations should be considered when evaluating the results of this study. First, 18% of participants endorsed having surgery to correct or lessen the severity of their epilepsy. The responses of these participants on questions regarding seizure awareness, control and strategy use were likely an artifact of surgery. Second, due to the length of time the study required for completion, several participants did not complete every item on the survey thus increasing the number of missing data. Finally, while the

proposed model accounted for a significant portion of the variance in QOL, there is room for improvement in the model.

Future directions in this area of research should explore the relationship between strategies and depression and anxiety. It would be interesting to determine if participant's comorbid depression and anxiety preceded their diagnosis of epilepsy and if so whether strategy use decreased the severity of their somewhat higher baseline depression and anxiety. Additionally, future studies should explore the addition of certain biological variables in the proposed model, such as number of anti-epileptic drugs currently taking. This addition would allow for a more comprehensive model and may increase the predictive ability of the overall model.

Appendix A



EXEMPTION NUMBER: 12-0X17

To: Shandelle Hether
From: Institutional Review Board for the Protection of Human
Subjects; Justin Buckingham, Member
Date: Thursday, October 06, 2011 *JB/wsp*
RE: Application for Approval of Research Involving the Use of
Human Participants

Office of University
Research Services

Towson University
8000 York Road
Towson, MD 21252-0001

t. 410 704-2236
f. 410 704-4494

Thank you for submitting an application for approval of the research titled,
*Predicting Quality of Life: Implications for Psychological Strategies for
Seizure Management*
to the Institutional Review Board for the Protection of Human Participants
(IRB) at Towson University.

Your research is exempt from general Human Participants requirements
according to 45 CFR 46.101(b)(2). No further review of this project is
required from year to year provided it does not deviate from the submitted
research design.

If you substantially change your research project or your survey
instrument, please notify the Board immediately.

We wish you every success in your research project.

CC: P. Galupo
File

Appendix B

INFORMED CONSENT

Thank you for your interest in participating in the current study for individuals who have epilepsy. My name is Shandy Hether, and I am a graduate student in Towson University's Clinical Psychology program. I am conducting research to determine the relationship of factors involved in the psychological management of seizure activity and quality of life. If you choose to participate in this study, you will be asked to complete the following survey, which should take approximately 30-40 minutes to complete. Your responses to this survey will be completely anonymous and confidential.

At the end of the study, you will be provided with a link titled "Giveaway" that will allow you to enter to win a drawing for a \$25.00 visa gift card. Your responses to this survey will not be associated with the information you provide on the "Giveaway" link. At the conclusion of the study four participants will be chosen at random to receive a gift card which will be mailed to the participant.

There are no anticipated risks associated with your participation, and your participation is completely voluntary. You are not obligated to respond to any questions that you are uncomfortable answering and may withdraw from the study at any time without penalty. Discontinuation of this study can be accomplished by clicking, "Exit this Survey" in the upper-right hand corner of the screen at any time.

The completion of this survey signifies your voluntary consent to participate in this research and that you are at least 18 years of age. The Towson University Institutional Review Board has approved this study. If you have any questions regarding this research or its purposes, please contact Shandy Hether at shethe1@students.towson.edu. You may also contact my faculty advisor, Dr. Paz Galupo, at pgalupo@towson.edu. If you have any questions pertaining to your rights as a participant, please contact Dr. Debi Gartland, Chairperson of the Institutional Review Board for the Protection of Human Participants, at (410)704-2236.

I have read the Informed Consent, agree to participate in this study and certify that I am at least 18 years of age.

- Yes
- No

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Table 1. Survey questions for seizure awareness

Seizure Awareness Scale (SAS)

1. I usually know when I will have a seizure.
 2. I usually have a general sense of how prone I am to have a seizure.
 3. I usually have the feeling that I will have a seizure a few hours or days before a seizure starts.
 4. I am aware of some things that increase the likeliness that I will have a seizure (i.e., being under stress, or tired)
 5. I am aware of most things that increase my chances of having a seizure.
 6. I usually experience some physical sensation such as a headache or lack of energy just before a seizure starts.
 7. I usually experience an aura (or a warning signal) just before I have a seizure.
-

Table 2. Survey questions for strategy use*Cognitive, Behavior & Emotional Strategies for Seizure Control (CBES-SC) Scale**Cognitive*

1. I control the severity of my seizure by changing the way I think (i.e., more positively) or what I am thinking about.
2. When I feel a seizure starting I focus my attention on something in my environment (i.e., what someone is saying or a song on the radio).
3. When I feel a seizure starting I focus my attention on something in my mind (i.e., a phrase, or prayer).

Behavioral

4. I control the severity of my seizures by preparing myself for the effects of the seizure (i.e., sitting down or bracing).
5. When I feel susceptible to having a seizure I avoid putting myself in risky situations (i.e., driving, climbing a ladder).
6. In order to prevent seizure activity I try to eat right, exercise and take care of myself.

Emotional

7. When I feel a seizure starting, I try to make myself feel calmer.
 8. When I feel a seizure starting, I try to make myself feel more positive emotions.
 9. When I feel susceptible to having a seizure, I try to make myself feel more neutral (neither good nor bad).
-

Table 3. Survey questions for perceived control

Perception of Seizure Control Scale

1. When I feel a seizure starting there is nothing I can do to control it. *
2. I feel I have some control over the severity or onset of some of my seizures.
3. I am directly responsible for my seizure activity getting better or worse.
4. Whether my seizure activity stops or lessens is a matter of luck or fate alone.*
5. No matter what I or anyone else does, if I feel a seizure starting it is going to start.*
6. If my epilepsy worsens it is probably because I have not been taking proper care of myself.

* denotes reverse score items

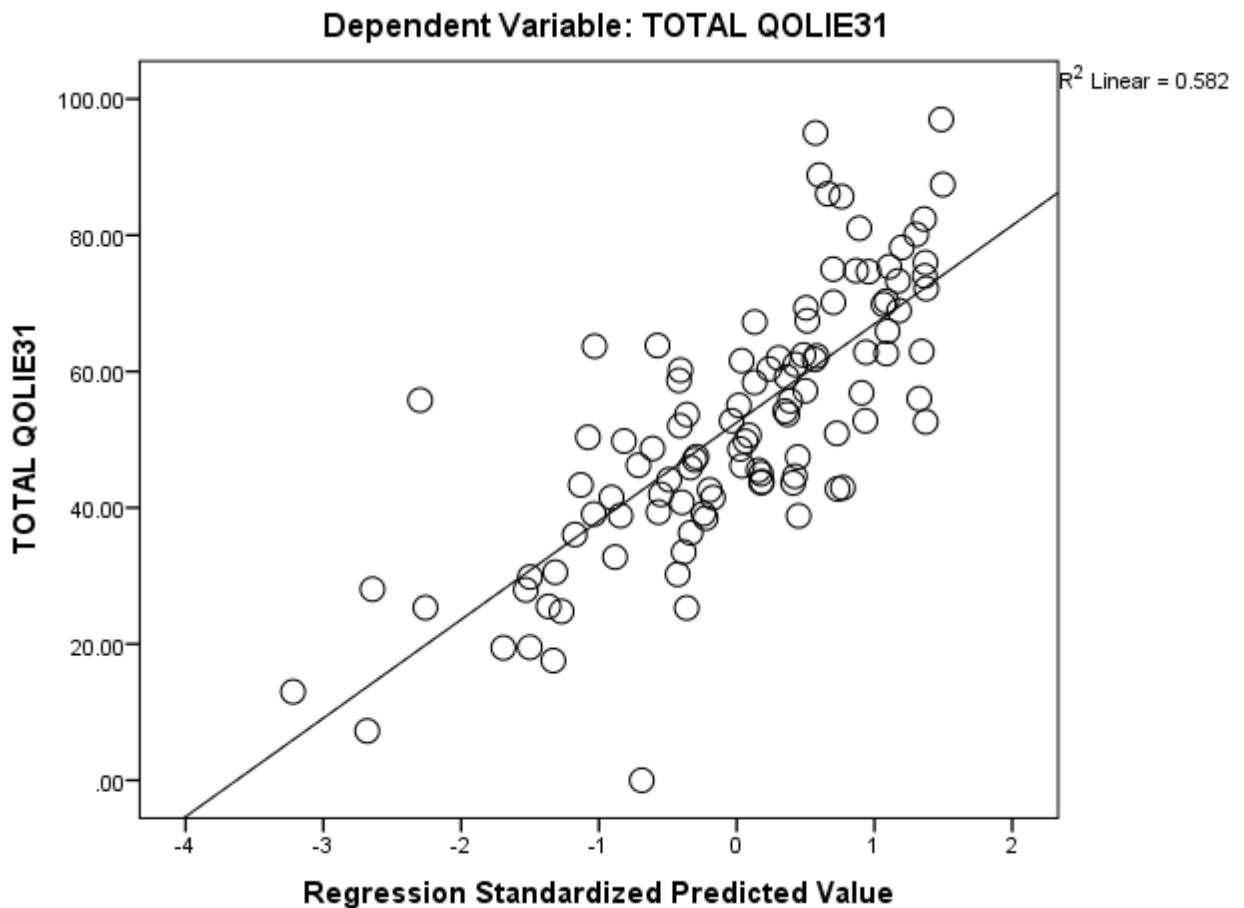
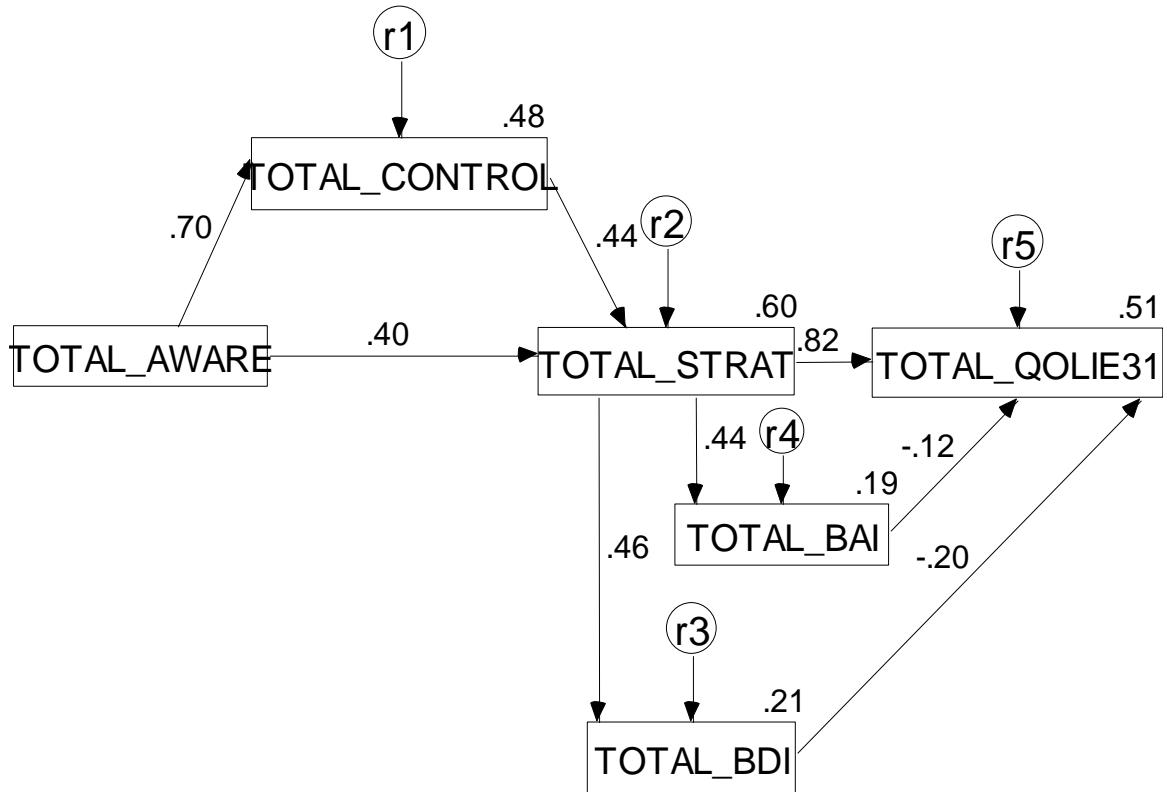
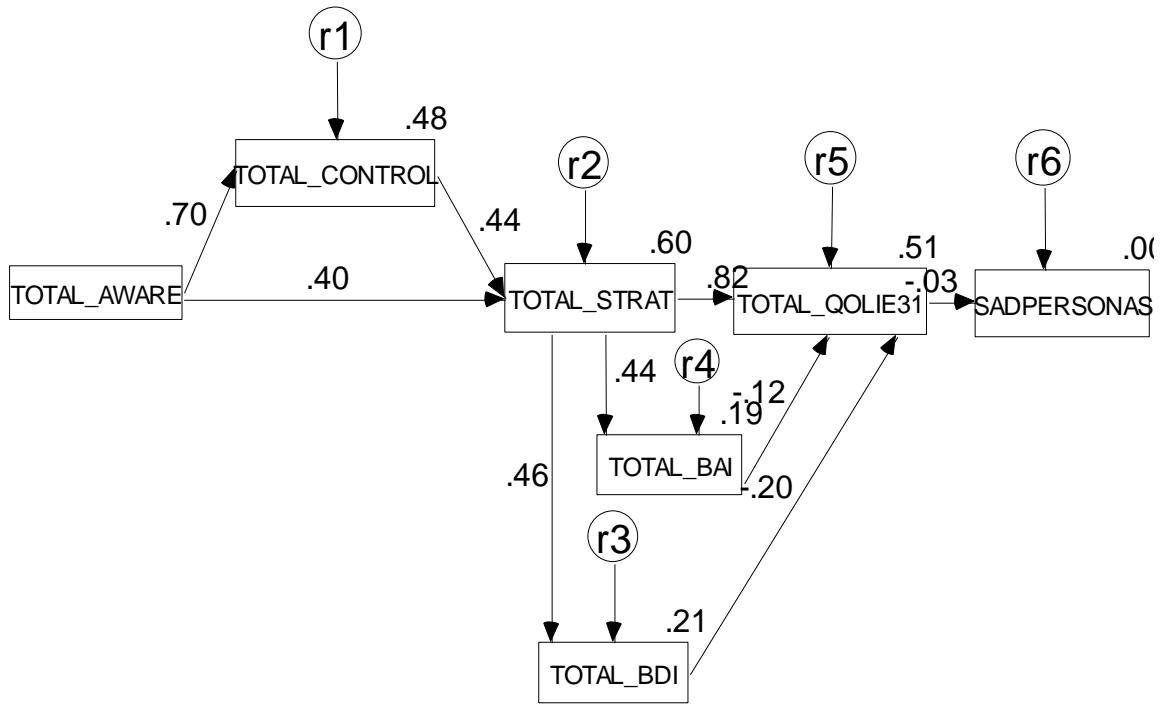
Figure 1 Model Fit

Figure 2 Path Diagram of Proposed Model for Predicting QOLIE



Note: Values above boxes represent squared multiple correlations or variance accounted for by the predictors of a particular box. For example, the predictors of total strategy account for 60.0% of its variance while the predictors if Total QOLIE-31 account for 51.0% of its variance. Values on arrows represent standardized regression weights. For example, when Participant's BDI scores increase by one point, their Total QOLIE-31 scores decrease by .20 standard deviations.

Figure 3 Path Diagram of Proposed Model for Predicting Suicide Risk



Note: As participant's Total QOLIE-31 scores increase by one standard deviation their suicide risk or scores on the SADPERSONAS decreases by .03 standard deviations.

Curriculum Vitae

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Educational Background:

2012	M.A. Candidate	Towson University, Towson, Maryland Clinical Psychology Thesis advisor: Dr. M. Paz Galupo Thesis Title: <i>Predicting Quality of Life and Suicide Risk in Epilepsy: Implications for Psychological Strategies for Seizure Management</i>
2008	B.A.	Flagler College, St. Augustine, FL Psychology, Summa cum laude

Publications:

Bauerband, L., Gonzalez, K., Hagen, B., **Hether, S. D.**, Krum, T. & Galupo, M. P. (Accepted). Transgender friendship experiences: Benefits and barriers of friendships across gender identity and sexual orientation.

Manuscript in Preparation:

Hether, S.D., Bruno, E., Johnson, C. T., & Galupo, M. P. (Submitted). Spontaneous strategies for psychological control and abortion of seizures.

Presentations:

Bauerband, L., Gonzalez, K., Hagen, B., **Hether, S. D.**, Krum, T. & Galupo, M. P. (November, 2011). Friendships of Transgender Identified Individuals: Experiences of Identity Disclosure. Abstract accepted for poster presentation at the annual conference for the Association of Behavioral and Cognitive Therapy, Toronto, Canada.

Hether, S. D. & Galupo, M.P. (April, 2011). The Development of a Novel Scale to Measure Spontaneous Strategies for Seizure Management. Poster presented at Towson University's annual Student Research and Scholarship Expo. Towson, MD.

Professional Experience:

2011- Present	Research Assistant Intern <i>Maryland Psychiatric Research Institute</i> Catonsville, Maryland
2010- Present	Graduate Teaching Assistant <i>Introduction to Psychology, Sensation & Perception</i> Towson University
2011-Present	Mental Health Worker <i>Sheppard Pratt Health System</i> Towson, Maryland

Professional Memberships and Certification:

American Psychological Association, Psychologist's for Social Responsibility, American Heart Association Healthcare Provider CPR and AED Certification (2011-2013)

