A Systematic Review of Self-Concept in Adolescents With Epilepsy

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Objective To critically assess the research quality of studies examining self-concept in adolescents with epilepsy (AWE) and, based on the evidence of these studies, to determine whether AWE have compromised self-concept, to identify correlates of self-concept, and to evaluate interventions aimed at improving self-concept. Method MEDLINE and EMBASE were searched for relevant publications. The modified Quality Index was used to evaluate study quality. Results 20 studies were reviewed and 8 studies were included in a meta-analysis. There was no significant difference in self-concept between AWE versus healthy control subjects. Self-concept was associated with a number of sociodemographic, clinical, and behavioral variables. Conclusion The limited number and modest quality of the studies available for review suggest that the negative findings should be interpreted with caution. In addition to addressing the limitations of existing studies, future research should focus on exploring the potential role of self-concept in the development of mental health problems in AWE.

Key words adolescent; child; epilepsy; self-concept; study quality; systematic review.

Self-concept is a multidimensional psychological construct that describes individuals’ internal depiction of their social acceptance, athletic and scholastic capabilities, behavior, and physical appearance (Marsh, Craven, & McInerney, 2008). It comprises individuals’ perceived identity and evaluation of their characteristics relative to others (i.e., self-esteem). Self-concept is regarded widely as an important component of adolescents’ psychological functioning and development and is strongly influenced by the expectations and expressions of significant persons (e.g., parents and friends) in adolescents’ lives (Bracken, 1996). Although a lot of research has focused on self-concept among healthy adolescents in the general population and in cross-cultural studies (Bracken, 1996), few studies have considered adolescents with a chronic medical illness, such as epilepsy. There are links between self-concept in childhood and several developmental outcomes. In both cross-sectional and prospective studies, poor self-concept in adolescence has exhibited associations with tobacco dependence, risk for major depressive/anxiety disorders, parasuicidal behavior, aggression, lower quality of life, tenuous relationships with peers, increased criminal behavior, lower educational attainment, and lower income (Donnellan, Trzesniewski, Robins, Moffitt, & Caspi, 2005; Pelkonen, Marttunen, Kaprio, Huurre, & Aro, 2008; Santos, Saravia, & De Sousa, 2009; Trzesniewski et al., 2006). In contrast, positive self-concept has exhibited associations with better stress management and more productive coping styles (Diehl & Hay, 2010; Poon & Lau, 1999). Positive self-concept is strongly associated with more favorable outcomes among adolescents with a chronic medical illness.
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may be at particular risk for reduced psychological functioning, specifically compromised self-concept. The aim of this article is to (1) critically assess the quality of research among studies that examined self-concept in AWE and (2) systematically review the available evidence in studies that (i) compared self-concept between adolescents with and without epilepsy to determine whether AWE have compromised self-concept, (ii) investigated correlates of self-concept, including the association of self-concept with health outcomes, and (iii) tested interventions aimed at improving self-concept in this vulnerable population. Limitations of previous research and suggestions for future studies are discussed to further this research agenda.

Method

Literature Review

The MEDLINE and EMBASE databases were searched simultaneously via the OVID electronic interface using combinations of the following keywords: adolescent, child, childhood epilepsy, epilepsy, self-concept, and self-image. All Medical Subject Heading terms were exploded to ensure a broad search of relevant studies (e.g., “self-esteem” is captured under the term, “self-concept”). Additionally, the ancestry method of reviewing the references of empirical studies and reviews for other relevant articles not identified with the initial search strategy was used to identify further studies reporting on self-concept in AWE. Finally, the Web of Science electronic database was used to identify recently published articles that cited studies already retrieved. The result of each stage of the search methodology used in this review is illustrated in Figure 1. In the search, no articles were obtained using the ancestry method. Also, an abstract and full article reporting on the same study was retrieved. In this instance, only the full article was included in this review.

Inclusion Criteria

To be included in this review, studies needed to meet the following criteria: (1) describe self-concept (including other interchangeable terms such as self-esteem and self-image) in AWE by either identifying correlates of self-concept; comparing ratings of self-concept between adolescents with and without epilepsy; or, comparing pre- and postintervention self-concept ratings among AWE; (2) AWE 10-22 years of age; and (3) written in English. Studies included adolescents with various epileptic seizure and syndrome types and adolescents with or without other comorbidities. Both effect estimates and associated p values are presented when reported by the original study investigators.
Quality Assessment

Retrieved articles underwent quality assessment using a modified version of the Quality Index (Downs & Black, 1998). Although developed initially to rate the research quality of both randomized and nonrandomized studies of health care interventions, the Quality Index is valid and reliable for measuring the methodological quality of epidemiologic and health research (Carville et al., 2008; Olivo et al., 2008; Sanderson, Tatt, & Higgins, 2007; Wang, Collet, Shapiro, & Ware, 2008). For this review, we reduced the original Quality Index from 27 to 15 items by excluding items related specifically to intervention studies, including randomization, blinding, withdrawals and drop-outs, and intervention integrity (Ferro & Speechley, 2009). Each checklist item was scored 0 (no/ unable to determine) or 1 (yes), with a maximum score of 15, whereby higher scores quantify higher methodological quality. Three subscales comprise the modified Quality Index: reporting (seven items), internal validity (four items), and external validity (three items). Study power was assessed with a single item. On the reporting subscale, items assess whether studies adequately describe and report objectives/hypotheses, main outcomes, sample characteristics, response rates, main results as well as estimates of variability (e.g., standard deviation) and statistical significance (actual p values). On the internal validity subscale, items assess the presence of multiple testing, the appropriateness of the statistical analyses, the adequacy (reliability/validity) of measurement, and the control of error. On the external validity subscale, items assess the source population and sampling methods, the representativeness of the study sample, and the representativeness of the treatment setting.

Analysis

Using the methods described previously, one investigator (M.A.F.) conducted the literature search and two investigators (M.A.F., A.L.F.) independently reviewed the retrieved articles using the modified Quality Index. Analysis of variance was used to determine whether quality scores differed between raters, whereas the inter-rater reliability of the modified Quality Index was assessed by calculating the intraclass correlation (ICC) and its associated 95% confidence intervals (CI) (Portney & Watkins, 1993). Because of skewness in the ratings produced by the modified Quality Index, nonparametric statistical approaches were implemented, whereby overall and subscale quality scores across study types were compared using the Kruskal–Wallis test. All hypothesis tests were two-sided, and data were analyzed using SAS 9.2 (SAS Institute Inc.).

A meta-analysis of studies that compared self-concept between AWE and healthy control subjects was conducted. For studies where healthy adolescent control subjects were recruited, effect sizes were calculated by comparing mean self-concept scores for both the epilepsy and control groups. A sample size of 500 was assigned for studies where normative data were used to compare self-concept in AWE, but the number of individuals in the normative sample was not provided. If a study reported a nonsignificant difference in self-concept between groups, but did not provide the data necessary to calculate an effect size, the conservative approach of assigning a zero effect size was employed. Effect sizes were calculated by Hedges’s g using a random effects model (Hedges & Olkin, 1984). Hedges’s g corrects for biases associated with small sample sizes, and its magnitude is interpreted using the guidelines provided by Cohen (1988) of small (0.20), medium (0.50), and large (0.80). Variation in the distribution of effect sizes among included studies was examined using the Q-statistic, an indicator of heterogeneity of variance. The meta-analysis was conducted using Comprehensive Meta-analysis V2 (Biostat).
Results

The 20 studies reviewed encompass research done over 28 years from 1983 to 2011. One study was removed after conducting the ancestry search (Gauffin, Landtblom, & Räty, 2010) because it reported (1) on the same baseline sample as another study (Räty, Soderfeldt, Larsson, & Larsson, 2004) and (2) after a 5-year follow-up the original sample of adolescents fell out of the age range specified by the inclusion criteria. The results reflect a global perspective with studies from the United States (4), United Kingdom (4), Canada (3), Sweden (2), Turkey (2), Australia (1), India (1), Israel (1), Netherlands (1) and Taiwan (1). Eight measures were used to assess self-concept. These were the Children’s Depression Inventory (Kovacs, 1992), Children’s Health Questionnaire (Landgraf, Abetz, & Ware, 1996), Coopersmith Self-Esteem Inventory (Coopersmith, 1981), Harter Self-Perception Profile for Children (Harter, 1985) and Adolescents (Harter, 1988), I Think I Am (Ouvinen-Birgerstam, 1999), Piers-Harris Children’s Self-Concept Scale (Piers, 2002), and Rosenberg’s Self-Esteem Scale (Rosenberg, 1965). Two studies did not use an established measure of self-concept; instead, adolescents were asked a series of questions relating to their self-concept (Hirfanoglu et al., 2009; Margalit & Heiman, 1983).

There was no significant difference between raters for the modified Quality Index, $F(1,40) = 0.05, p = 0.828$ and the ICC and the associated 95% CI was 0.93 [0.84, 0.97]. Given the high ICC and insubstantial score differences between reviewers, ratings were pooled and average scores derived for each item of the modified Quality Index. Retrieved studies had a median modified Quality Index score of 10.8, ranging from 8.0 to 12.5. The median subscale scores were 6.0 (range, 3.0 - 7.0) for reporting; 3.0 (range, 2.0 - 4.0) for internal validity; and 2.0 (range, 0.0 - 3.0) for external validity. One study reported a formal sample size or power calculation (Hamiwka et al., 2009). A median score of 10.8 suggests overall that the quality of evidence is modest for the studies available for review.

Table I highlights the key features of each study. The 20 studies addressed multiple objectives: 11 compared self-concept between adolescents with and without epilepsy; 9 compared epilepsy with healthy control subjects (Baker, Spector, McGrath, & Soteriou, 2005; Çengel-Kültür, Ulay, & Erdag, 2009; Hodes, Garralda, Rose, & Schwartz, 1999; Lee, Hamiwka, Sherman, & Wirrell, 2008; Margalit & Heiman, 1983; Räty, Wilde Larsson, & Soderfeldt, 2003; Reeve & Lincoln, 2002; van Empelen, Jennekens-Schinkel, van Rijen, Holders, & van Nieuwenhuizen, 2005); and 3 compared epilepsy to other chronic conditions (Chiou & Hsieh, 2008; Hoare & Mann, 1994; Pradhan, Shah, Rao, Ashurkar, & Ghaisas, 2003). Furthermore, 11 studies investigated correlates of self-concept (Funderburk, McCormick, & Austin, 2007; Hamiwka et al., 2009; Hirfanoglu et al., 2009; Hoare & Mann, 1994; Hodes et al., 1999; Lee et al., 2008; Räty et al., 2004; Räty et al., 2003; Reeve & Lincoln, 2002; Westbrook, Bauman, & Shinnar, 1992; Yu, Lee, Wirrell, Sherman, & Hamiwka, 2008), and 4 studies examined interventions aimed to improve self-concept in AWE (Conant, Morgan, Muzykewicz, Clark, & Thiele, 2008; Frizzell, Connolly, Beavis, Lawson, & Bye, 2011; Snead et al., 2004; van Empelen et al., 2005). There were no statistically significant differences among study types in their overall Quality Index scores ($\chi^2 = 0.66, p = 0.723$) or subscale scores for reporting ($\chi^2 = 3.74, p = 0.154$), internal validity ($\chi^2 = 1.47, p = 0.480$), or external validity ($\chi^2 = 0.47, p = 0.789$).

Self-Concept in Adolescents With and Without Epilepsy

As shown in Figure 2, most studies reported that self-concept was lower in AWE compared with adolescents without epilepsy. Effect sizes were predominately small, with two studies having medium effect sizes (Çengel-Kültür et al., 2009; Margalit & Heiman, 1983). Based on the Rosenberg Self-Esteem Scale, Baker et al. (2005) were the only investigators to suggest that AWE possessed higher levels of self-concept than control subjects. Although there was no evidence of significant heterogeneity among studies included in the analysis, $Q(7) = 11.00, p = 0.139$, the small number of studies available combined with variability in their sample sizes provided reasons for using a random effects model. Pooling these studies ($n = 8$), the overall effect size was $g = -0.08 [-0.26, 0.10]$, indicating that AWE versus those without epilepsy did not have significantly lower self-concept. Both Lee et al. (2008) and van Empelen et al. (2005) stated that there were nonsignificant differences in total self-concept between AWE and normative control subjects but did not report the actual mean differences and failed to identify the sample size of normative control subjects. For these two studies, we took the conservative approach of assuming a zero effect size and a normative sample size of $n = 500$. Given that the meta-analysis did not provide evidence to reject the null hypothesis that AWE have lower self-concept compared with healthy control subjects, a fail-safe $N$ was not calculated.

Three studies compared self-concept between AWE and adolescents with another chronic condition. Using
## Table I. Summary of Studies Reviewed

<table>
<thead>
<tr>
<th>Citation</th>
<th>Study Design and Subject Age</th>
<th>Sample</th>
<th>Measure</th>
<th>Results Reported</th>
<th>QIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baker et al., 2005 (United Kingdom)</td>
<td>Cross-sectional, convenience and random sample Epilepsy (n = 70): 15 years Controls (n = 70): 15 years</td>
<td>N = 140 (matched)</td>
<td>RSES</td>
<td>Comparison</td>
<td>10.0</td>
</tr>
<tr>
<td>Çengel-Kültür et al., 2009 (Turkey)</td>
<td>Cross-sectional Epilepsy (n = 41): 14.0 years Controls (n = 34): 13.9 years</td>
<td>N = 75 (matched)</td>
<td>RSES</td>
<td>Comparison</td>
<td>9.5</td>
</tr>
<tr>
<td>Chiou &amp; Hseih, 2008 (Taiwan)</td>
<td>Cross-sectional, random sample Epilepsy (n = 48): 10.6 years Asthma (n = 54): 11.4 years</td>
<td>N = 102</td>
<td>SPPC</td>
<td>Comparison</td>
<td>12.0</td>
</tr>
<tr>
<td>Conant et al., 2008 (United States)</td>
<td>Intervention (pilot), 10 weeks</td>
<td>N = 9</td>
<td>PH</td>
<td>Intervention</td>
<td>10.0</td>
</tr>
<tr>
<td>Frizzle et al., 2011 (Australia)</td>
<td>Intervention, 2 sessions</td>
<td>N = 30</td>
<td>RSES</td>
<td>Intervention</td>
<td>11.5</td>
</tr>
<tr>
<td>Funderburk et al., 2007 (United States)</td>
<td>Cross-sectional</td>
<td>N = 173</td>
<td>PH</td>
<td>Correlates</td>
<td>10.0</td>
</tr>
<tr>
<td>Hamiwka et al., 2009 (Canada)</td>
<td>Cross-sectional, convenience sample Epilepsy (n = 59): 11.8 years Kidney (n = 40): 12.0 years Controls (n = 42): 11.9 years</td>
<td>N = 141</td>
<td>PH</td>
<td>Correlates</td>
<td>10.5</td>
</tr>
<tr>
<td>Hirfanoglu et al., 2009 (Turkey)</td>
<td>Cross-sectional</td>
<td>N = 220</td>
<td>–</td>
<td>Correlates</td>
<td>9.0</td>
</tr>
<tr>
<td>Hoare &amp; Mann, 1994 (United Kingdom)</td>
<td>Cross-sectional Epilepsy (n = 62): 11.8 years Diabetes (n = 91): 11.5 years</td>
<td>N = 153</td>
<td>SPPC</td>
<td>Comparison; Correlates</td>
<td>9.0</td>
</tr>
<tr>
<td>Hodes, et al., 1999 (United Kingdom)</td>
<td>Cross-sectional, convenience sample Epilepsy (n = 22): 11.9 years Siblings (n = 16): 11.9 years</td>
<td>N = 38</td>
<td>SPCC</td>
<td>Comparison; Correlates</td>
<td>12.0</td>
</tr>
<tr>
<td>Lee et al., 2008 (Canada)</td>
<td>Cross-sectional</td>
<td>N = 37</td>
<td>PH</td>
<td>Comparison; Correlates</td>
<td>12.0</td>
</tr>
<tr>
<td>Margalit &amp; Heiman, 1983 (Israel)</td>
<td>Cross-sectional, random sample 10.9 years Epilepsy (n = 20) Learning impaired (n = 20) Healthy controls (n = 20)</td>
<td>N = 60</td>
<td>–</td>
<td>Comparison</td>
<td>9.0</td>
</tr>
<tr>
<td>Pradhan et al., 2003 (India)</td>
<td>Cross-sectional, consecutive sample Age range, 8–12 years Epilepsy (n = 30) Thalassemia (n = 30)</td>
<td>N = 60</td>
<td>RSES</td>
<td>Comparison</td>
<td>8.0</td>
</tr>
<tr>
<td>Räty et al., 2003 (Sweden)</td>
<td>Cross-sectional Epilepsy (n = 151): 18.5 years Controls (n = 282): 18.0 years</td>
<td>N = 433</td>
<td>ITIA</td>
<td>Comparison; Correlates</td>
<td>12.5</td>
</tr>
</tbody>
</table>

(continued)
the Piers-Harris Children’s Self-Concept Scale, Chiou & Hsieh (2008) reported that AWE had significantly higher global self-worth compared with adolescents with asthma ($d = 0.21, p = 0.025$). However, AWE had significantly lower scores for scholastic competence ($d = 0.53, p = 0.004$), social acceptance ($d = 0.67, p < 0.001$), and athletic competence ($d = 0.47, p = 0.028$). No significant difference was observed for the physical appearance ($d = 0.08, p = 0.409$) and behavior conduct ($d = 0.19, p = 0.693$) subscales. Similar results were reported by Hoare and Mann (1994) using the Harter Self-Esteem Questionnaire in a comparison study of AWE and diabetes. Adolescents with epilepsy had significantly lower global self-concept ($p < 0.01$), as well as lower scholastic ($p < 0.001$), social ($p < 0.01$), athletic ($p < 0.05$), and behavior ($p < 0.05$) subscale scores compared with adolescents with diabetes. Too little information was provided to estimate effect sizes. Pradhan et al. (2003) compared self-concept between AWE and adolescents with thalassemia using the Rosenberg Self-Esteem Scale; however, insufficient data were reported to determine whether AWE had lower levels of self-concept.

### Correlates of Self-Concept

Several researchers have investigated correlates of self-concept in AWE. Räty et al. (2003) identified an age and gender association whereby lower self-concept was observed among older ($p = 0.005$) and female ($p = 0.006$) adolescents. In another study, Räty et al. (2004) observed lower self-concept among females compared with males, but only among those with moderate illness severity ($p = 0.03$).

With regard to clinical aspects of epilepsy, Westbrook et al. (1992) showed in multivariate analysis that self-concept was associated with seizure frequency ($\beta = -0.24, p < 0.05$) and focal seizures ($\beta = -0.44, p < 0.001$). In addition, Lee et al. (2008) found that self-concept was associated with the number of antiepileptic drugs prescribed ($\beta = -0.32, p < 0.05$), and Räty et al. (2004) showed that self-concept was inversely related to illness severity ($F = 3.97, p = 0.02$).

In terms of individual and family characteristics associated with self-concept, there has been much research investigating the relationship between self-concept and perceived stigma of epilepsy. Controlling for seizure-related variables, Westbrook et al. (1992) demonstrated a significant inverse association between self-concept and perceived stigma ($\beta = -0.29, p < 0.05$). This result was confirmed in more recent studies by Funderburk et al. (2007) and Hirfanoglu et al. (2009). These studies also showed that self-concept was associated with adolescent attitudes toward epilepsy, such that lower self-concept...
was correlated with poorer attitudes ($\beta = 0.31$, $p = 0.001$ and $r = -0.19$, $p = 0.005$, respectively) (Funderburk et al., 2007; Hirfanoglu et al., 2009). Examination of family processes has shown that parenting is related to domain-specific self-concept. Positive maternal remarks toward adolescents were significantly correlated with scholastic ($r = 0.63$, $p = 0.002$) and athletic ($r = 0.54$, $p = 0.010$) self-concept (Hodes et al., 1999).

### Association Between Self-Concept and Mental Health Outcomes

Researchers have been active in understanding the association between self-concept and health outcomes, specifically in the identification of behavioral outcomes in AWE. Early work by Hoare and Mann (1994) using the Harter Self-Esteem Questionnaire found a negative association between global self-concept and both internalizing ($r = -0.41$, $p = 0.001$) and externalizing ($r = -0.42$, $p = 0.001$) behavior problems. Reeve and Lincoln (2002) observed self-concept to be correlated with a nonproductive coping style ($r = 0.48$, $p = 0.003$) among AWE, but not in control subjects. As well, using the Piers-Harris Children’s Self-Concept Scale, Yu et al. (2008) demonstrated that lower self-concept was associated with lower health behavior (e.g., poor eating habits, less exercise, increased risk-taking behavior, and substance use) ($r = 0.63$, $p < 0.001$) and this remained significant after controlling for the effects of family functioning.

### Interventions to Improve Self-Concept

The earliest work to improve self-concept in AWE was conducted by Snead et al. (2004) in which a structured psychoeducational group intervention was provided to adolescents aged 13–17 years. In this pilot study, adolescents ($n = 7$) were introduced to basic concepts in the following content areas: medical aspects of epilepsy, healthy lifestyle behaviors, family, and peer relationships, understanding self-image and self-esteem, and stress management techniques. Although participants reported a reduction in negative self-concept, the change was not statistically significant. Using a similar approach, Frizzell et al. (2011) recruited 30 AWE aged 12–19 years to receive a two-part educational intervention facilitated by an epilepsy fellow or nurse. The first part included individual sessions in which participants were informed about their personal health and provided with general epilepsy knowledge. The second part included group sessions about the impact of epilepsy on lifestyle (e.g., driving, seizure triggers). Using the Rosenberg Self-Esteem Scale, 60% of participants reported improved self-concept after the intervention; however, mean pre- and postintervention scores were not significantly different ($d = 0.26$, $p = 0.103$).

Conant et al. (2008) conducted a pilot study assessing the effect of a 10-week karate program on self-concept among nine adolescents 8 - 16 years with epilepsy. As measured with the Piers-Harris Children’s Self-Concept Scale, self-concept ratings improved, although not significantly, between the pre- and postintervention assessments.
(d = 0.15, p = 0.920). Van Empelen et al. (2005) studied the change in self-concept of 13 adolescents before and after epilepsy surgery. Significant improvements (p < 0.05) in self-concept were observed at six months for the following subscales: physical appearance (d = 0.72), romance (d = 1.18), friendship (d = 1.21), and global self-worth (d = 1.49). At 24 months, significant improvements (p < 0.05) were observed in the athletic (d = 0.46) and romance subscales (d = 1.10).

Discussion
Summary of Research Findings
Our review suggests that the self-concept of AWE may not be compromised. Because this conclusion is based on few studies of limited quality and relatively small samples, we are concerned about the population coverage of AWE as well as the methodological adequacy of available studies. Recruitment of prevalent cases of epilepsy and failure to stratify on epilepsy syndrome or seizure type prevent studies from capturing the important period from diagnosis to study recruitment, when the self-concept of these adolescents will depend on clinical and family factors that affect continuing clinic involvement. For example, AWE have lower quality of life at diagnosis compared with 24 months later (Speechley et al., 2009) and levels of mental health problems are known to vary across seizure types (Caplan et al., 2005; Elinci, Titus, Rodopman, Berkem, & Trevathan, 2009; Thome-Souza et al., 2004; Titus, Kanive, Sanders, & Blackburn, 2008). Additionally, many AWE have other comorbidities, particularly cognitive disability, and other neurologic deficits (Besag, 2002; Rodenburg, Stams, Meijer, Aldenkamp, & Dekovic, 2005). Most studies excluded these adolescents so that results unlikely reflect the realities faced by this large subgroup. Future studies need to address these substantive and methodological challenges to improve the evidence base on the self-concept of AWE.

This review also highlighted associations between self-concept and sociodemographic, clinical, and psychological factors implicated in epilepsy. Among AWE, self-concept is lower among females and older adolescents. This finding is consistent with studies of healthy adolescents (Kling, Hyde, Showers, & Buswell, 1999; Robins, Trzesniewski, Tracy, Gosling, & Potter, 2002) and other chronic illness samples (Ek, Westerlund, Holmberg, & Fernell, 2008; Manuel, Balkrishnan, Camacho, Smith, & Koman, 2003; Ryan & Morrow, 1986). Self-concept also exhibited positive associations with illness severity and seizure frequency, reflecting observations between self-concept and asthma severity and attention-deficit hyperactivity disorder (Bussing, Zima, & Perwien, 2000; Kelsay, Hazel, & Wamboldt, 2005; Pisecco, Wristers, Swank, Silva, & Baker, 2001). Furthermore, associations were reported between low self-concept and perceived stigma, poor attitudes towards epilepsy, mental health problems and negative coping.

It is important to note that these studies were cross-sectional, providing useful information on associations but no pertinent evidence on temporal order, obviating our ability to infer anything about causation (Rothman, Greenland, & Lash, 2008). For example, in the studies by Westbrook et al. (1992), Funderburk et al. (2007), and Hirfanoglu et al. (2009), it is not possible to conclude that increases in perceived stigma of epilepsy caused declines in self-concept. Equally plausible is that declining self-concept caused adolescents to perceive increased stigma. Likewise, in the study by Hoare and Mann (1994), it cannot be concluded that a decline in self-concept is the causative factor in elevated rates of internalizing and externalizing behavior problems among AWE. Although some evidence do suggest declines in self-concept are antecedent to poor mental health outcomes (Pelkonen et al., 2008; Trzesniewski et al., 2006), these studies were conducted in general population samples and may not generalize to AWE. Implementing prospective cohort studies will help to clarify the temporal order of cause and effect and allow us to assess self-concept as a causal agent. Salient outcomes that may be influenced by self-concept in AWE include psychiatric disorders such as depression and anxiety, as well as psychological functioning related to adaptation, stress management, coping, and resilience. The importance attached to quality of life in pediatric epilepsy (Ronen, Fayed, & Rosenbaum, 2011) suggests that investigating the relationship between self-concept and quality of life should also be a priority for future research.

With only four intervention studies, limited in design and scope (combined, they included only 59 patients with short follow-ups), valid inferences into the potential malleability of self-concept cannot be drawn. Perhaps more importantly, controlled trials are needed to address the central question of whether strengthening self-concept results in the improvement of other mental health outcomes.

Methodological Considerations
The studies conducted to date provide preliminary, although important, contributions to understanding self-concept in AWE. With this important groundwork completed, future research should build on these initial studies. Development of robust methodologies requires an assessment of the limitations of available literature in
order to advance this program of research. These limitations fall under the headings of measurement, control of error, and sampling.

Measurement
Because the focus of most substantive research in the area of self-concept is concerned with testing for mean group differences, researchers must know that the instrument used to measure self-concept is functioning in exactly the same way across groups. In studies comparing self-concept between adolescents with and without epilepsy, there has been an underlying assumption of measurement equivalence in the absence of any evidence that this is true. Testing this assumption is critical in the area of chronic illness research in which socialization factors may have a prominent impact. Although the factor structure of an instrument may yield a similar pattern when tested within each group, such findings represent no guarantee that the instrument will operate equivalently across groups (Byrne & Campbell, 1999).

In addition, researchers must be vigilant to use instruments that are most appropriate for the sample under study and, in the case of measuring self-concept, instruments that capture the multidimensional and hierarchical structure of self-concept (Marsh & Shavelson, 1985). For the most part, studies used acceptable instruments to measure self-concept; however, in the study by Snead et al. (2004), the negative self-esteem subscale of the Children’s Depression Inventory was used. This measure only captures negative perceptions of self-esteem, the evaluative component of self-concept. Researchers should be cognizant of this limitation and measure self-concept with a reliable and valid instrument, such as the Piers–Harris Children’s Self-Concept Scale (Piers, 2002), Harter Self-Perception Profile for Children/Adolescents (Harter, 1985; Harter, 1988), or the Self Description Questionnaire I/II (Marsh, 1992a, 1992b).

The Piers–Harris is a 60-item measure for children and teens aged 7–18 that requires approximately 10 to 15 minutes to complete. It has been revised since its initial development, and the current version has acceptable reliability ($\alpha = 0.91$) and validity (Piers, 2002). Harter’s measure includes a 36-item scale for children (8–12 years) and a 45-item scale for adolescents (13–15 years). They both require approximately 15 to 20 minutes to complete and have adequate reliability (child: $\alpha = 0.74–0.83$; adolescent: $\alpha = 0.74–0.92$) and validity (Harter, 1985; Harter, 1988). The Self-Description Questionnaire (SDQ) I/II are a 76- and 102-item measure for children 8 to 12 years and adolescents 13 to 19 years of age, respectively. The SDQ has been described as the most validated self-concept measure available (Byrne, 1996). Both versions require approximately 20 minutes to complete and have acceptable reliability (SDQ I: $\alpha = 0.86$; SDQ II: $\alpha = 0.87$) (Marsh, 1992a, 1992b). Irrespective of the choice of scale used to measure self-concept, researchers must be conscious about using more dated instruments and ensure that the most recent version is used so that results are meaningful for current pediatric epilepsy populations.

Control of Error
Due to the potential for bias in most observational studies, adequate control of confounding variables is paramount to producing internally valid results when assessing causative relationships. Scores on the internal validity subscale of the modified Quality Index suggest that the studies reviewed need improvement in order to generate internally valid results. Studies conducted by Westbrook et al. (1992), Lee et al. (2008), and Yu et al. (2008) controlled for confounding effects using multivariable regression analyses and are an improvement over simple unadjusted bivariate correlations. Although these studies do provide adjusted estimates of the association of self-concept with individual, family, and clinical characteristics, the inclusion of variables solely based on significant bivariate associations (such as $\chi^2$- or $t$-tests) is problematic; resulting in the exclusion of some important confounders and biased effect estimates (Sun, Shook, & Kay, 1996). Modeling the association of self-concept with other important variables should focus on model-building processes that are researcher-driven and account for confounders as determined by theory and empirical evidence.

Sampling
Because most studies were conducted in individual clinics operating in tertiary care centers and appeared to rely on nonprobability convenience sampling, it is difficult to determine whether study participants adequately represented the target population. It is important for researchers to select a sample from a well-defined sampling frame; specify whether the sample represents incident or prevalent cases or both; and apply standard methods for case ascertainment and inclusion/exclusion criteria. Although guidelines exist for case definitions and measurement indices in epidemiological studies in epilepsy (International League Against Epilepsy, 1993), guidelines for standardized reporting requirements for patient recruitment and sampling in epilepsy warrant consideration. Existing statements, such as the Strengthening the Reporting of Observational Studies in Epidemiology, can be used to inform and tailor reporting standards in epilepsy research (von Elm et al., 2007). Development and implementation of such
guidelines would improve the quality of published studies and reduce the time and effort needed to critique them.

Scores on the external validity subscale of the modified Quality Index suggest a need for caution in generalizing results from the studies reviewed. Few studies explicitly reported using a convenience-based sample (Hamiwka et al., 2009; Hodes et al., 1999; Pradhan et al., 2003); only two studies implemented simple random sampling (Chiu & Hsieh, 2008; Margalit & Heiman, 1983); and one study used a combination of convenience and random sampling with a matched design (Baker et al., 2005). Hospital-based convenience samples of families attending outpatient clinics at tertiary care centers compromise the external validity of results because the impact of selection factors is unknown.

Conclusion

Based on only eight studies of limited quality, our review indicates that AWE do not have compromised self-concept. We also identified several correlates of self-concept that are potentially modifiable and observed that self-concept is associated with mental health problems among AWE. However, the methodological quality of available studies is generally modest and needs to be strengthened in future work. This would help to resolve current divisions among researchers and clinicians about the relevance of self-concept for improving the life quality of children and adolescents experiencing epilepsy and other chronic medical illnesses (Baumeister, Campbell, Krueger, & Vohs, 2003; Swann, Change-Schneider, & Larsen McClarify, 2007). The core questions bear on the extent to which self-concept can be manipulated with interventions and, in turn, the extent to which these changes in self-concept influence subsequent mental health outcomes. Prospective cohort studies with repeated measures that aim to elucidate these causal mechanisms can be used to test new and important hypotheses and provide the evidence to make more accurate conclusions. Future research should attempt to overcome the substantive and methodological limitations of previous work by recruiting adolescents newly diagnosed with epilepsy and sampling AWE with comorbid conditions. As well, prospective studies within a causal modeling framework may prove valuable in clarifying temporal relationships between self-concept and other health outcomes, particularly the onset of psychiatric disorders and quality of life. Such steps will help researchers and clinicians to better understand the experience of patients and ultimately enhance the lives of adolescents living with epilepsy.

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References

* References marked with an asterisk indicate studies included in the meta-analysis.


longitudinal assessment of the first 2 years post-diagnosis. *Epilepsia*, 50(suppl 11), 213.