Reviewer's report

Title: Effective Process or Dangerous Precipice: Comparative Embedded Case Study with Young People with Epilepsy and Their Parents during Transition from Children's to Adult services.

Version: 2 Date: 17 June 2013

Reviewer: Michele Maddux

Reviewer's report:

The manuscript titled, “Effective Process or Dangerous Precipice: Comparative Embedded Case Study with Young People with Epilepsy and Their Parents during Transition from Children’s to Adult services” was aimed at exploring communication, information needs, and experiences of knowledge exchange in clinical settings by young people and their parents, during transition from children’s to adult epilepsy services.

Though we recognize the importance of this research and believe the content of this manuscript is highly relevant to clinical care, many of the conclusions (esp regarding causality) drawn are not scientifically sound or warranted given the data collected and the specific study design and analysis methodology. In addition, the theoretical framework is highly questionable, and figures are highly cumbersome, difficult to read, and unclear. For these reasons, most of the comments below are major compulsory revisions.

Discretionary Revisions
1. Figure 5 is unnecessary. Its content could be incorporated into Figure 4.
2. Figure 8 is confusing. The authors should consider modifying it, or describing Pattern Matching in the text rather than via figure.
3. The number of figures is very cumbersome to the reader. In addition, many of these figures are difficult to follow, read, and understand. These need to be more concise and succinct, for improved readability.

Minor Essential Revisions
1. Young people with severe learning disabilities were excluded from analyses. Given the prevalence of attention deficits and learning disabilities among youth with epilepsy, how might findings impact the generalizability of study findings?
2. More information is needed to describe the study design, namely comparative embedded case study. Related to this, is “case study” the correct term? Case study typically refers to a single subject/patient.
3. Researcher/Practitioner and Reflexivity: how were patients’ epilepsy-specific knowledge and communication skills measured? Additional details are needed.
4. The authors use transition and movement from children to adult services interchangeably. This is not correct. Transition is defined as the process by which
young patients become more involved in their care and disease management, while transfer refers to the physical movement from pediatric to adult services. These terms should be distinguished throughout.

5. The authors should consider removing figures (1-3; 10-12). These are identical to each other, and have previously been published. Consider referring the reader to this published work instead.

6. Figure 14: This is a table, not a figure. The authors should consider adding lined rows within this table for readability purposes. As is, it is difficult to decipher which “what works” correspond to which “how it works,” “for whom,” and “in what context.”

Major Compulsory Revisions

1. The authors conclude that the researcher practitioner had no doubts that the majority of participants had no difficulty voicing their personal opinion of services. How was this measured? This needs to be quantified in order to make such conclusions across participants, and to render some objectivity to this conclusion. Without a measurable outcome, this conclusion is not warranted.

2. Data analysis: The authors note that the most significant findings were presented, yet they do not describe how significance was evaluated. Does this refer to statistical or clinical significance, and how was this quantified?

3. Some quantifiable measure is necessary throughout the results section. Conclusions are made repeatedly (e.g., joint care was most effective for patients and parents, patients engaged more by being befriended, young people said that staff used age-appropriate facilitative skills, young people were more likely to be better educated when healthcare professionals anticipated their knowledge/information needs, and many more) without any descriptive data such as frequency counts, percentage/percentile, means/standard deviations, measures of clinical significance. In addition, what data was collected to make various conclusions, for example that patients engaged more as a result of being befriended by staff? How was this measured? What data was collected to make these statements of causality? These statements need to be tempered throughout or removed.

4. Figure 1: the theoretical framework makes many assumptions that are not supported by evidence-based research or clinical anecdote. For example, that if information exchange is age appropriate and at the patient’s developmental age, that information will be accepted by the patient. This seems more related to a patient’s cognitive ability to take in information, which increases the likelihood that a patient’s knowledge will improve, not acceptance.

5. Figures 2 and 11 have many weaknesses, and warrant revision. The title suggests that it summarize comorbidities experienced as a result of receiving information, communicating, and information exchange with healthcare professionals. Yet cognitive sequela of epilepsy is not a result of information exchange, receipt, or communication with healthcare professionals; it is a result of the disease itself. The title needs to be modified to more accurately capture the content of the figure.
6. Case 1 and Case 2 figures are very confusing and difficult to follow. Does the figure read from the bottom up? 6 young people are described at the top, 12 under children’s services, and 13 under adult services. What do these numbers mean?

7. The directionality of arrows within Figures 2 and 11 suggest pathways, temporal association or causality. Yet, based on Lewis SA, Noyes J and Mackereth S (2010), embarrassment is one contributing factor to why young adults don’t communicate with healthcare professionals during medical visits. Here in Figures 2 and 11, the arrows suggest that cognitive impairments lead to patients being unable to talk about their disease, which then results in embarrassment and fear of peer rejection. This contradicts what has previously been published by the authors.

Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests