Reviewer's report

**Title:** Treatment non-adherence in pediatric long-term conditions: systematic review and synthesis of qualitative studies of carers' views

**Version:** 1  
**Date:** 10 November 2013

**Reviewer:** Scott Burgess

**Reviewer's report:**

This is a well planned and written article, which I enjoyed reading much more than I had anticipated. I would be happy to support as written with the following as discretionary points for consideration.

1. Background 2nd paragraph (page 2). The discussion about the definition could be better expressed. I believe the authors to be arguing that they would prefer to use the terms adherence and compliance as they feel this better reflects the nature of the relationships in the articles reviewed or at least these terms do not presume a degree of negotiation that may not have taken place. It could be read that they don’t use the term concordance because they don’t agree with the notion of shared decision making which I hope is not the case. Perhaps I have misread the paragraph. Either way I think this could be more clearly expressed.

2. Not a recommendation, just a comment. I have not previously read the sentence quoted on the third paragraph page 10 under 1. Carer beliefs, attributed the reference 21. I think this is the best description of this concept I have read and I think the paper is the better for having included it.

3. Limitations: I think this paper is well written, but I think this methodology has limitations that need to be better discussed. I would suggest the paragraph on limitations be expanded. My argument is as follows:

   This paper nicely brings together themes discussed by parents with researchers about adherence with treatments. The two main limitations of this concept is (1) Sample and (2) Capacity for insight / social desirability.

   (1) Sample. Although the overall sample is good, each individual study is relatively small. The nature of in depth interviews is also going to exclude some clients (mainly as the most non-adherent subjects don't take part in research projects). I run a Difficult asthma clinic in a public hospital. To get into this clinic children have to have poorly controlled asthma despite maximal standard therapy. We monitor adherence with electronic monitoring devices and have a psychologist in our clinic. We have clients who either don't participate in our research group or fail to keep coming to sessions because for multiple reasons, but include significant social disadvantage (for example one boy was taken into foster care and lost to follow-up) and others who come to hospital with acute asthma are very hard to engage. These subjects won't have been captured in such analysis.
(2) The authors have correctly stated that this is analysis of carer's views. But this is not the same as the true reasons (or at least the complete picture) for suboptimal adherence. The two limiting factors are insight and openness. We have clients in our clinic with whom we have been working who have low levels of adherence but who also have some but limited insight into their own problems. This sounds a little patronising but many of our parents have mental health difficulties or have imitated capacity for in depth reflection.

The authors would be aware of the concept of social desirability, a very powerful convention that explains why mist parents exaggerate adherence at least a little. The mean adherence in our group at enrolment is 45%, but almost all report 90% plus adherence. A small number of teenagers manipulate their adherence deliberately to ensure their asthma is worse so they miss school. Other parents don't really know what their children are doing but would not want to report that they have stopped supervising their child. One study found that the degree of supervision reflected their capacity to observe the child and not the child's maturity. Thus these parent are trying to convince themselves that their child is more mature because they don't have the capacity to supervise them. Thus it is common for clients to exaggerate adherence and offer more socially acceptable reasons for low adherence. A small number are deceitful because of other agendas including secondary gain.

Paragraph two under 1. Carers beliefs page 10 is essentially describing the Health beliefs model in which patients weigh the pros and cons of treatments. Whereas my understanding is that human decision making has been more often shown to be based on preconceived notions and split second decisions with such deliberations being more commonly used as post decision rationalisations.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: Yes, and I have assessed the statistics in my report.

Declaration of competing interests: I have no competing interests.