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: 15 November 2013

Reviewer: Mary Irvine

Reviewer's report:

The manuscript is clear in its statement of the problem, and the title and abstract are strong and to-the-point. The Background establishes the need for this work and its contribution to the existing literature around adherence. The Methods seem appropriate to the qualitative approach taken, and they are generally well-described (with one minor exception noted below). The Findings also follow a format appropriate to qualitative work, and specifically thematic synthesis. However, I question whether there should be any use of quotations from caregivers (perhaps not), since I would tend to expect the impact of such quotations to be greater in context, in the original paper being reviewed, than in a review article. The Discussion and Conclusions are reasonable and well-supported, though they felt to me slightly light on the side of what can be done to respond to the findings. (I would have liked a bit more in the Findings and Discussion on the role of professional providers, though that may not be feasible given the articles included in the review.) In all, I found the manuscript well-written, worthwhile, and valuable in extending the literature regarding adherence barriers and potential interventions to address them.

Major Compulsory Revisions: None.

Minor Essential Revisions:

1. In the Background, the description of related quantitative research (paragraph 3) mentions interventions found to be effective, but does not mention common barriers to adherence identified in this body of literature. Please add a sentence or two, with appropriate citations, about the common barriers identified.

2. Also in the Background, the paragraph (4) on qualitative research examining adherence among adults focuses entirely on barriers and does not mention any findings or even recommendations related to strategies for overcoming these barriers. For balance in the literature review, I would suggest adding something about interventions to this paragraph.

3. In the Methods, "Quality of reporting" paragraph, it is somewhat unclear just what was done with the information/assessment on quality of articles. It might help to briefly enumerate the criteria applied (for readers who don't know and may not want to have to review the CASP quality assessment tool). It also seems important to clarify (1) whether any papers were excluded due to quality concerns, and (2) how exactly the use of a paper was affected by its quality scoring, if the paper was retained in the review but judged to be of marginal
quality or just of lower quality than some others included.

4. In the Results, the mention of an "11-year period" does not match the years shown, which suggest more like a 15-year period of publications.

5. In the "Analytical overview" paragraph just before the Discussion section, the final sentence needs re-tooling, mainly due to multiple clauses lacking separation with commas, and a final clause that refers to "juggling of the balance of..." (I would just go with "juggling" or "balance").

Discretionary Revisions:

1. In the first paragraph about "Child resistance" on p. 12, the term "repetitive resistance" could use a bit of definition or explanation. I would have thought that "child resistance" would encompass one-time and (usually) repetitive resistance, and I think explaining the concern of a habit or pattern of resistance that is self-reinforcing, for example, would help to distinguish and make that term more meaningful. But it may just be that I am unused to the term.

2. Also in that section on "Child resistance," I thought the example with the quotation (2nd paragraph) was not as clear an example as you'd want. Was there a quotation that gets more at the idea of wanting to let the child have some agency, or not wanting to aggravate the pains of growing up, or having to choose between emphasizing adherence and showing sympathy and support for the child who is having difficulty? I can imagine that the caregiver quoted may have had any or all of those in mind, but it doesn't come across in the statement that the child and the parent are each having a difficult time.

3. Under either "Child resistance" or "Impact on relationships within families," I was expecting to see some mention of the issues around adherence when the illness is particularly stigmatized, as in HIV, or at least when the illness carries the expectation of a premature death, as in HIV or cystic fibrosis. I would think that would be a major difference between the chronic disease areas included in the review, since stigmatized illnesses and those associated with premature death bring complexities around disclosing the full nature of the illness to the child and (in the case of HIV) addressing the connections between the child's illness and an alternative (foster, adoptive, or extended-family) caregiver arrangement, death or illness of a biological parent, and/or difficult period in a parent's personal history. If issues related to disclosure and addressing premature death were not covered enough in the articles to make that point in the review, then I understand not getting into that. But in my own work related to HIV-related pediatric treatment adherence, issues of stigma and disclosure were pervasive in management of communications with the child, and an area in which the professional healthcare providers could be particularly helpful, but also could at times come into conflict with the family caregivers (who tended to differ in the direction of protecting children from potentially painful information, when they differed on strategy around disclosing diagnosis and/or its seriousness).

4. I noticed that "regime" was sometimes used interchangeably with "regimen," in places where I think the meaning fit better with "regimen."

Level of interest: An article whose findings are important to those with closely
related research interests

**Quality of written English:** Acceptable

**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.