

## **Reviewer's report**

**Title:** The self-expressed needs of people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A systematic review

**Version:** 1 **Date:** 3 September 2009

**Reviewer:** Jonathan Price

### **Reviewer's report:**

#### Major Compulsory Revisions

1. Any systematic review, no matter how thorough, is potentially a victim of the quantity and quality of the contributing evidence. In this review, which appears to have been conducted thoroughly, there is an absence of evidence on the needs of the very many people who have mild CFS-ME, and a reasonable amount of evidence for the fewer people who have moderate or severe CFS-ME (see Table 1; characteristics of included studies). This needs to be made clear – in the abstract, in the results, and in the discussion. The statement in abstract / results '32 quantitative and qualitative studies, including the views of over 2500 people with CFS/ME with a wide range of illness severity' is incorrect.

2. The authors use a thorough approach to data gathering, which is to be commended. They include both research studies, and patient 'stories'. However, in my view, the reporting of the latter needs to be improved. These stories are not mentioned in Abstract / results; it is not clear how they were discovered; and it is not clear how they were appraised for inclusion or exclusion. – Were they discovered incidentally, as the data contributing to reference 4? Did other patient stories from other sources contribute to the dataset? Furthermore, while quality assessment of papers is explicitly discussed, the issue of 'quality assessment' of patient stories is not mentioned.

3. This paper has 11 authors, and their contributions are listed under 'authors' contributions' at the end of the manuscript. I was surprised that five authors assessed validity of included studies and that six authors took part in analysis and interpretation. In Methods / data syntheses, it states 'The reviewers repeatedly read the statements ...' – does this mean all eleven of them, or all six of them? And 'the group scrutinised the categories' – again, who comprises 'the group', and how did this group function? The authors need to be more explicit, within the manuscript itself i.e. within the methods section, on the roles played by each of them at each stage of the review.

4. Furthermore, it is important to know something of the authors' backgrounds and preconceptions – if this was a primary qualitative study, rather than a secondary qualitative study, we would be very interested in how their pre-study beliefs would influence data inclusion and interpretation. This is not a criticism, but a comment on the interpretation of this kind of evidence, and the evolution of integrative models such as that in Figure 2. It is highly likely that the attitudes of

the researchers have influenced the conclusions here, and the authors need to acknowledge and discuss this inevitability.

5. Finally, the discussion needs to be strengthened, and must be more critical of the primary data, the results of the data synthesis, and the authors' conclusions. Unfortunately, at the moment, the discussion reads as a relatively uncritical summary of the results, rather than as a rigorous consideration of how the review has advanced knowledge in this area and, crucially, in which ways it has not advanced knowledge.

#### Minor Essential Revisions

1. In Abstract / design, I wondered if the word 'personal' substituted for the word 'own' would make the sentence clearer.
2. There are some minor errors of punctuation e.g. colon at end of Abstract / results; missing comma in abstract / conclusions after 'leisure services'; further comma needed after 'two reviewers and' in Methods / quality assessment.
3. The sentence in Methods / Criteria for inclusion of studies which reads 'The needs had to be expressed by people with CFS/ME, in interpretation of their discussions with researchers, or in their responses to questionnaires' is not easy to understand, and needs rewriting.
4. In Methods / quality assessment, change 'was' to 'were', and change 'risk' to 'risks'.
5. In Results / line 1, there is a missing 'were'.
6. In Results / the need to make sense of symptoms, change 'was' to 'were'.
7. In Results / The need for recognition / para 3, line 6, there is a spurious 'a'.
8. In Discussion, does the word 'particularities' exist? If it does, can it be substituted for a more commonly used word, such as 'specific'?
9. I think that the political and value-laden statement in the Discussion which reads 'That so many of these needs are unmet is unacceptable in wealthy nations' is inappropriate, and that the authors should consider removing it.

**Level of interest:** An article of importance in its field

**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