Author's response to reviews

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

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Author's response to reviews: see over
This document restates comments received by reviewers and editors, and includes our replies to these comments (in blue). Changes to the manuscript can be found in tracking.

Thank you all for your thoughtful and constructive comments and ideas about this research, Lee and the review team

**Associate Editor comments:**
Being used to meta-analysis I wondered if there were any measures undertaken to exclude multiple reports of the same studies. 
We have added some details of this process on page 4.

Additionally it would be highly appreciated if the authors could mention that they followed the PRISMA statement for systematic reviews somewhere in the methods section. 
Good idea, added on page 5.

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

**Version:** 1  **Date:** 13 August 2009  
**Reviewer:** boudewijn van Houdenhove

**Reviewer’s report:**
This is an interesting manuscript reporting a systematic review of qualitative studies on CFS/ME. It provides important information concerning the illness experience and coping of these patients and their needs and expectations with regard to their family, social environment and health care providers. The information summarized in the manuscript can be very useful in view of optimal management of the illness.

However, a limitation of this study is that it neglects possible links between 'illness story' and 'life story'. Every experienced CFS/ME clinician who carefully listens to these patients' history will agree that such links can be found in the great majority of patients. In my view, paying attention to this aspect of 'the patients' story' can for many of them have an additional therapeutic value (see e.g. Van Houdenhove 2002; Van Houdenhove & Luyten, 2008).

This is an interesting point, and we have added some thoughts on this into the discussion (on page 18).

**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

**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. Thank you for this observation, we agree with you, and have amended the abstract (page 2), the results (page 6) and the discussion (page 17) to make this point.

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. The ‘own stories’ were published papers (as the other types of study included in the review), and the individual papers that are ‘own stories’ are noted in the results section (page 6) and in table 2. They were identified and included in exactly the same way as the other included published papers.

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. Details of the review team, and that they worked together as a group to read, re-read and interpret, have been added to page 5.

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. We have added some comments on this and our backgrounds on pages 17-18.

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. We have added a fuller critical discussion on pages 17-18, including discussion of the objectivity of the review, the use of systematic methodology and the use of multiple
reviewers with a variety of backgrounds, as well as the primary aims of the studies included into the discussion.

Minor Essential Revisions
1. In Abstract / design, I wondered if the word ‘personal’ substituted for the word ‘own’ would make the sentence clearer.  Done

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.  Thank you, corrected.

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.  Sentence rewritten.

4. In Methods / quality assessment, change ‘was’ to ‘were’, and change ‘risk’ to ‘risks’.  Done.

5. In Results / line 1, there is a missing ‘were’.  Added

6. In Results / the need to make sense of symptoms, change ‘was’ to ‘were’.  Done

7. In Results / The need for recognition / para 3, line 6, there is a spurious ‘a’.  Done

8. In Discussion, does the word ‘particularities’ exist? If it does, can it be substituted for a more commonly used word, such as ‘specific’?  Done

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.  Done

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