Reviewer's report

Title: The German Fibromyalgia Consumer Reports - A cross-sectional survey

Version: 1 Date: 17 February 2012

Reviewer: Nicola Chaloner

Overview

This paper sets out to provide the first European Fibromyalgia Syndrome consumer group report on treatment effectiveness and side effects, which they intend to supplement the findings of broader RCT studies.

This is the largest scale consumer review undertaken in Europe to-date and a useful subject for both patients and clinicians alike. The paper also does well to challenge the high recommendation for drug therapies within FMS guidelines which again may have implications for clinical practice.

Whilst the purpose, methods and broad findings of the study are relatively easy to make sense of, there are repeated grammatical, typographical and presentation issues that would need to be addressed in order to aid the reader’s comprehension of the study.

In addition, the authors need to give the reader more information on exactly what was being asked of participants as it is impossible to comment fully on the study’s design without being able to read a copy of the central questionnaire measure used (alternatively this could be supplied).

The paper would benefit from greater transparency about the study’s methodological limitations and the extent to which any firm conclusions can be drawn beyond this, within the discussion.

Finally, the paper would benefit from further reflection on the wider theoretical context surrounding the findings, in particular the extent to which key self-reported methods identified as ‘effective’ are reflective of wider evidence related to functional improvements and adjustment.

Major Essential Revisions:

1: Literature Review:

1.1: Whilst I recognise the word limit may be strict this is very brief – it would have been useful to know more about what the key NFA study found in terms of outcome. Equally any reference to the relationships between prior ‘effectiveness’ ratings and wider functioning/quality of life could set the tone for further reflection within the discussion section (see comments below).
2: Methodology:

2.1: Without a copy of the questionnaire measure devised it is difficult to fully review the methodology of the study. Specifically, there is no mention of Cognitive Behavioural Therapies within the ‘psychological therapies’ section of the results, despite the fact that this is commented on elsewhere in the paper. As a reader I wanted to know which psychological therapies were being rated and I would have ideally liked a copy of the questionnaire as an appendix.

2.2: Secondly, whilst the authors do well to outline a number of methodological limitations that are clearly beyond the scope of this study to address (limitations of self-report, retrospective design etc), the following areas would benefit from greater discussion and clarification:

2.2(1): Inclusion of individuals with co-morbid inflammatory conditions without commenting on to what extent the results then differed for this subgroup. It would also be useful to know more about what specific diagnoses this group included and whether they were accessing any additional treatments (e.g. specific anti-inflammatory medication) which may have influenced ratings given. A sub group report would be helpful;

2.2(2): Whilst I recognise that this is the largest scale European consumer review to-date, the results still represent a relatively small sample of the population group and this needs to be better acknowledged and reflected upon. The extent to which ‘lost’ data was a major or minor issue would also be useful for the reader to understand in interpreting the findings.

2.2(3): Whilst recognising that this is a cross-sectional survey, it would have been interesting to include a measure of functioning or quality of life, to provide a broader context for the findings. I do, however, recognise that this is possibly beyond the scope of this study and would be hard to change now. I think this issue could be usefully be flagged up for further thought in the discussion (see interpretative issues below).

2.2(4): Whilst the reviewer recognises that the study set out to provide descriptive statistics on the population sample, it would have been interesting to note whether any relationships existed between participant ratings, demographic variables and self-reported anxiety and depression.

3. Interpretative:

3.1: The reviewer is concerned that initial use of terms such as ‘effectiveness’ and ‘harm’ without clarification, may be misleading for the reader. The use of the term ‘harm’ in particular suggests risk/dangerousness rather than ‘unpleasantness’, which I think this is what you were exploring. This may be a translational issue but these terms need to be clarified earlier on in the paper.

3.2: Similarly, the reporting of the scale ‘a 0-10 scale, with 10 being most efficacious (harmful)’ took several attempts of reading through to understand –
the reader should be able to make sense of this with one read through and the sentence needs revising throughout.

3.3: Equally I was confused about the difference between baths, thermal baths and whole body warmth therapy, which take on three separate categories. This needs clarifying.

3.4: The study could benefit from further reflection on how these results can inform clinical practice. The authors need to comment on the fact that the predominant self-management methods used (particularly rest) are widely regarded as poor predictors of functional outcome and adjustment. Reference to the wider acceptance based literature on the relationships between symptom control efforts ‘experiential avoidance’ and outcome, could be usefully added and reflected on in this regard.

4: Minor Essential Revisions:

There are a number of minor grammatical and typographical errors see below and given translation issues whilst I not feel the paper should be rejected on these grounds the authors may benefit from getting additional support in this regard:

4.1: Page 4, paragraph 2, lines 1 and 5, use of word ‘send’ should read ‘sent’.

4.2: Page 4, paragraph 2, line 10, ‘removed the addressor’ should read ‘removed the participants address/identifying details’.

4.3: Page 4, second paragraph within ‘Questionnaire’ section (line 3), ‘directors of the two self-help organisation’ should read ‘organisations’.

4.4: Page 5, paragraph entitled ‘Ethics’, line 2 reads ‘The study had been proved’ this should read: ‘The study had been approved’.

4.5: Page 5, paragraph entitled ‘Study Participants’ could benefit from clarification of the acronym ‘CWP’ to term Chronic Widespread Pain.

4.6: Page 6, paragraph entitled ‘comparison with other studies’, lines 7 and 8: use of term ‘valuated’, should read: ‘evaluated’ or ‘rated’.

4.7: Typographical issues with quotation mark style

4.8: ‘Benefits and harms’ – poor grammar and concern over misinterpretation of these terms see above

5: Discretionary Revisions

5.1: The figures are confusing, presumably as multiple therapies may be being (or have previously been) employed by any single participant. This could benefit from being made clearer for the reader.

5.2: Given that ‘benefits and harms’ may not be mutually exclusive it would have
been interesting to view the both sets of mean ratings for each intervention alongside each other.

5.3: The organisation of the method section could be made clearer to include inclusion/exclusion criteria after the ‘study centres’ section.

5.4: Equally it would have helped the flow to provide sub-headings for organisation of the study across self-help arms of the study within the methodology section.

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

**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 have a special interest in acceptance based approaches within pain management and work in this field.