Reviewer's report

Title: The Information Needs of People Living with Ankylosing Spondylitis: A Questionnaire Survey

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Reviewer: erik Lenguerrand

Reviewer's report:

Major compulsory revisions
A. Research aim and structuring of the results section

The authors are investigating the information needs and preferences of people with AS. A close investigation of the results section reveals that the authors are exploring the information sources, utilisation and needs of people with AS, as stated in the introduction of the abstract section. However, only the information « needs » is mentioned in the title or in the key words section.

This is a minor point per se, but the concept of « needs » is unclear in this article. It is alternatively referring to the format of the information (ie source and support), to the content of the information (ie quality, topics covered, disease, health care, coping strategy/behaviour) or to those who deliver the information. As a consequence, the structuring of the results section is confusing and in some places rambling.

A large part of this section described the use of internet and the characteristics of these users; and as a whole more than two thirds of this research is related to the information sources.

The sections called « internet use », « other information source » and part of the « written information » and of the « age and gender differences » sections could be grouped under two themes: « Information source » and « Information use ». Each of these two sections could contain the description of the user characteristics. Information needs and « improving information delivery » could be considered in a last section. At the moment, the findings on information needs are lost in the text, despite the importance given to this concept by the authors in the title of this article.

B. Methods (The following comments are driven by my quantitative background and this point might need to be revisited by a qualitative researcher.)

This article is using a mixed method approach, ie this is a descriptive quantitative piece of research mixed with a qualitative approach (thematic analysis of open-ended question narratives).

Regarding the quantitative part:
-The statistical comparisons should be formally conducted and tests such as Khi-square test could be used.
Means and standard deviations are derived. It is only relevant if the data are normally distributed. If not, median and interquartiles range would be more meaningful. Moreover, appropriate non parametric test should be used to conduct group comparison (such as Kruskal–Wallis one-way analysis of variance). Are the various scores normally distributed?

- It is unclear how the confidence intervals are derived and why they are not systematically presented.

- Following the previous point, the results section could be improved with the use of tables and graphical and by limiting the number of figures listed in the text.

- In the results section, the patients can be stratified by internet use or not. (155 vs 56). I thought that only those with internet access would be eligible for some specific research point. For example, only 20 people aged 20-39 use internet. So the prevalence of social networking should be 14/20 and not 14/22. The same issue applied everywhere in the results section. This is not 50% of the pop who used internet for AS info but 103/155,...17/20,...etc.

The analysis strategy should also be described (for example, "the prevalence will be presented by information source, ....and comparisons will be conducted by patient characteristics....")

Regarding the qualitative part :

A thematic analysis is used to extract emerging themes. This type of analysis should be described to allow the reader to understand the underlying strategy and its potential impact on the results (ie tool, threshold, inclusion, exclusion, grouping criteria,...) The strength of the qualitative findings is very difficult to assess.

Qualitative findings are presented along quantitative findings: it is therefore difficult to determine which methods have been used to draw the various findings and therefore which ones are recurrent themes quoted by large group of patients and which findings are only quoted by a reduce number of patients (as table 2 seems to suggest).

Moreover, themes seems to have been extracted by a single researcher. I am wondering if a subsample of patients should be randomly sampled (10 to 20%???) and re-investigated by a second person unaware of previous findings. An appropriate agreement statistics test could be computed to assess the quality of the current data extraction.

As a quantitative researcher, I would expect to see an indication of group size along quote like « many participants », « participants », « other info that people would like...n=...n=...n= ». But it might be irrelevant in a qualitative approach.

The method section needs to be improved and extended.

C. The discussion

The structure of the discussion is debatable. A summary of the findings is usually expected in the first paragraph and followed by a comparison with the existing
litterature. The first paragraphs of this discussion are extensively presenting limitations points which are discussed again later on.

This section is long and sometimes very speculative.

I would have appreciated to read a summary with some potential explanations for each of the following points: information sources, uses, preferences and needs.

It is mentionned that the majority of the respondents were older with longstanding disease which might explained the need for improved info for non-specialist healthcare professionals and the general public. However, it is also mentionned in the results section that all age groups would like some improvements in the GP knowledge and support, access to specialist healthcare professionals and services. The authors need to clarify this discrepancy.

Minor essential revisions
- It is unclear how the closed ended question have been selected. See also point in discretionary revision section.
- A brief description of the BASDAI, BASFI and EQ-5D indexes could be very useful.
- There is a typo in the result section: this is not 40/1121 but 40/1211.
- Another typo in following sentence (discussion section) « For example, younger men may not be receptive.... may difficult to reach... » may be difficult to reach.

Discretionary revisions
- The introduction section could be extended to provide more details about AS, who is mainly concerned, its prevalence in UK,...
- In the methods section: The authors mentionned the use of proportions. Strictly speaking they are presenting prevalence, hence the needs to justify the representativeness of their sample.
- It would be interesting to provide a reference for the PAS cohort.
- It could be informative to provide the questionnaire as an appendix or in an online section.
- The SAIL data are presented in the text just before the "analysis of data" section. Some of the information are presented twice (a billion records) and sometime with inconsistency (GP record in one place but GP and in- or out-patient data elsewhere). This section could be improved.
- In the conclusion, the authors could highlight the importance of internet for the youngest generation and the patients needs for AS forum/ website to share experience or discuss the disease. The charity or NHS organisations could play an important role in setting up the facilities which will addressed the needs of the youngest and new patients?

**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 declare that I have no competing interests