PEER REVIEW HISTORY

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ARTICLE DETAILS

<table>
<thead>
<tr>
<th>TITLE (PROVISIONAL)</th>
<th>Stroke survivors and their families receive information and support on an individual basis from an online forum: descriptive analysis of a population of 2,348 patients and qualitative study of a sample of participants.</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUTHORS</td>
<td>De Simoni, Anna; Shanks, Andrew; Balasooriya-Smeekens, Chantal; Mant, Jonathan</td>
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VERSION 1 - REVIEW

<table>
<thead>
<tr>
<th>REVIEWER</th>
<th>Yingchih Wang</th>
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<tr>
<td></td>
<td>University of Wisconsin - Milwaukee</td>
</tr>
<tr>
<td>REVIEW RETURNED</td>
<td>24-Nov-2015</td>
</tr>
</tbody>
</table>

GENERAL COMMENTS

The purpose of this paper was to summarize the information based from an online forum participated by stroke survivors and their families. Major recommendation

• The thematic analysis of users’ intents for posting in the forum, referring to as the category of topics that stroke survivors posted online (summarized in Table 4), provides very beneficial information.
• Although the intent of this paper was good, there are many concerns of this study due to the nature that data were retrieved from an online forum. Some participants may have no clear identity. The participants are not representative of the stroke population as results may be biased toward stroke survivors who are more cognitively sound, have higher upper limb function, and more verbal about their experience. The conversation could not be structured. Information on type of stroke and disabilities were retrieved from the posts, but not directly from the participants. Whether the users’ intents were met by the replies was hypothetical and could not be verified. As a result, the internal validity of the study may be questionable. If within the study design, participants were followed up by a survey study to verify their identities and results, then the evidence of this study would be much stronger.
• There are some statements need clarification. It is interesting to see participants within the age range of 0 to 10 years on the online discussion forum. Is the ‘age’ self-reported or all the participants have to register with date of birth? That is, if participants failed to report their true age, then suffering a stroke at age 0 could be the case. Please elaborate.
• There are some concerns about some statements or inferences in this paper. For example, since this is an online forum study, "producing a sample of participants that were representative of the sex and ages at stroke" as mentioned in the paper, may be compromised. On page 8, in the statement of "the population of survivors and of patients described by third party had near normal distributions, spanning all ages", normal distributions is a strong
statistical statement. Based on the age distribution, participants were not as “young” as mentioned on page 12 (implications for clinicians and future research) as there were many participants aged 60 to 95.

In the abstract, the conclusion was that “patients’ needs expressed in the online forum confirm and widen the evidence…showing that such forums are a potential resource for studying needs in this population.” However, it seems to me that this study was not to confirm that the online forum is a great resource (not verified), but to provide the thematic analysis and categories the online topics that stroke survivors and their associates discussed more often than other topics.

- It is not clear why the first two participants per group were selected for further thematic analysis.

Minor recommendation
- Page 2, Abstract: suggest removing the sentence “although younger than the UK stroke population (mean age 52 years vs 77 years in SSNAP)”
- Page 4, Introduction, line 19: the citation should take place after the comma (i.e., ,23). Similar things occurred on line 54.
- Page 8, line 2: 1,391 instead of 1391 to be consistent across the paper.
- Page 8, line 51: suggest replacing “P<0.0001” to “P<0.001”
- Re-arrange the sequences of tables and figures.
- Bibliography: Extra space after reference#9, and extra doi information with reference#10.

<table>
<thead>
<tr>
<th>REVIEWER</th>
<th>Euan Sadler</th>
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<tr>
<td></td>
<td>King’s College London, United Kingdom</td>
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| REVIEW RETURNED | 09-Dec-2015 |

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<tr>
<th>GENERAL COMMENTS</th>
<th>Overall the paper is well written. My recommendation is to accept the paper with minor revisions to address the points set out below:</th>
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<tr>
<td>Abstract:</td>
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<td>Introduction:</td>
<td>The authors could make a better link between the first and second sentences- unmet needs of stroke survivors and higher levels of social support associated with improved health outcomes with people with stroke and other long term conditions. In the second paragraph, specifically in what ways do health professionals understand stroke differently compared to stroke survivors in the study of stroke groups cited?</td>
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<tr>
<td>Methods:</td>
<td>The methods and process of quantitative and qualitative analysis are clear and well described.</td>
</tr>
<tr>
<td>Results:</td>
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<tr>
<td>Discussion:</td>
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In places the discussion is quite descriptive and requires further interpretation. Specifically:

Could the authors comment more on the significance and implication of forum participants being younger compared to the overall stroke population (first paragraph on p.11) and of higher education (last paragraph on p.11), and that third party users participating in the forum represented patients in the first year post stroke and those with higher levels of disability (first paragraph on p.12).

Under the implications section could the authors specify what similar issues participants taking part in the online forum raised compared to the wider stroke population (first sentence, second paragraph on p.12).

**VERSION 1 – AUTHOR RESPONSE**

Reviewer: 1

The purpose of this paper was to summarize the information based from an online forum participated by stroke survivors and their families.

Major recommendation

- The thematic analysis of users’ intents for posting in the forum, referring to as the category of topics that stroke survivors posted online (summarized in Table 4), provides very beneficial information.

We have added the following paragraph within the Results at page 9, lines 232-233: The topics for the requests of information/support and the linked provisions of such information/support are reported in table 4, in order of frequency.

- Although the intent of this paper was good, there are many concerns of this study due to the nature that data were retrieved from an online forum.

The study used a relatively novel methodological approach by qualitatively analysing posts of patients on an online forum, which allowed for naturalistic data collection without involvement of a researcher. This approach has already been used in other published studies, of which six have been referred in the manuscript (references 26, 30-31, 57, 58, 59). We argue that this is a valid method to better understand patients’ issues and behaviours, with the view of better informing healthcare interventions and policies, complementing the evidence derived from more traditional research methods (see also reference 42: De Simoni et al. Making sense of patients’ internet forums: a systematic method using discourse analysis. (2014) Br J Gen Pract. 64 (620), e178-e180). In our view, a major strength of analysing an online discussion forum is that the creation of data was not influenced by a researcher, in contrast to interview data, but is rather created through natural interactions amongst stroke survivors and their relatives. We acknowledge, though, that this approach has also limitations, as highlighted in the strengths and limitations section on page 2, lines 58-59: The analysis of the forum was limited by the time users were active in the forum, by the form moderation process, and by the lack of assessment of the authenticity of the forum content, and in the strengths and limitations section within the discussion (page 11-12, lines 288-297).

- Some participants may have no clear identity.

The 2,348 participants of this study identified themselves either as stroke survivors or as third party talking about a patient with stroke. Participants with no clear identity were excluded from the analysis, as illustrated in figure 1 and described at page 8, lines 184-187: 235 participants were excluded from the analysis as they identified themselves as students or healthcare professionals asking questions...
for research purposes (n = 43), forum moderators, or posting single short messages (n=153) from which it was not possible to gauge whether they were survivors, third party or users unrelated to stroke (figure 1). We have added the reference to figure 1 and a sentence to the beginning of the results to clarify this, page 8, lines 188-189: Therefore the 2,348 participants included in this study were either survivors or patients with stroke talked about by third parties.

- The participants are not representative of the stroke population as results may be biased toward stroke survivors who are more cognitively sound, have higher upper limb function, and more verbal about their experience.

In reply to this point, we have added the following paragraph in the discussion, page 12-13, lines 315-324: Although 957 (41%) participants were stroke survivors who were younger and potentially more cognitively sound and verbal about their experience than the population of patients with stroke, the majority of participants (1,391, i.e. 59%) were patients with stroke talked about by third party, therefore potentially representing the population of stroke sufferers less able to communicate via computers and more disabled. Indeed evaluation of disability from the sample of participants showed that 91% of patients discussed by third party were suffering from physical disability, which was severe in 59%. This is in contrast with users who were stroke survivors themselves, 76% of which were suffering from physical disability, and only 28% from severe physical disability. Interestingly, non-physical disability like cognitive and memory impairments were more prevalent amongst stroke survivors (56%) than in patients with stroke discussed by third party (40%).

- The conversation could not be structured. Information on type of stroke and disabilities were retrieved from the posts, but not directly from the participants.

As stated above, this study used a relatively novel methodological approach by qualitatively analysing posts of patients on the online forum of the Stroke Association website, which should allow for naturalistic data collection from participants who identified themselves as stroke survivors or carers of patients with stroke. Dialogues stemmed from participants' own agenda. Impairments were self-reported and participants might have experienced additional ones not mentioned in the forum, making the evaluation of disability not comprehensive. We have added the following paragraph in the discussion at page 12, lines 292-295: The analysis of the forum was limited by the time users were active in the forum and the amount of information given away, e.g. participants might have experienced additional impairments not mentioned in the forum, making the evaluation of disability not comprehensive. We have also changed accordingly the legend of table 2, page 15, lines 361-362: Type of stroke and disability degree as evaluated in the sample of 59 representatives forum participants.

- Whether the users' intents were met by the replies was hypothetical and could not be verified.

We agree that whether or not users' intents were met by the replies was a subjective judgement. For this reason 2 authors independently coded posts from a random subset of participants (15/59 participants, accounting for 206 of the 841 posts analysed). We have added further details about the double coding, see page 7, lines 159-163: CBS repeated independently phases 1 to 3 of thematic analysis in a subset of random participants (15 participants, 206 posts), identified users' intents and classified whether or not they were addressed by responses (for description of the latter, see the next paragraph). Coding was discussed until agreement was reached, and the coding framework and coding for the other 44 participants was revised as well. In the methods at page 7, line 156 we described how the users intents were isolated within the 841 posts from the sample of 59 participants: One to four users' intents were identified within each post, yielding a total of 1,379 users' intents; and page 7, lines 167-170: Replying users' intents were compared with requesting users' intents one by one and classified according to whether or not they were accomplished (codes used: yes, not,
unsure). An intent was classified as accomplished when the intent of the replying user was matching the requesting one, i.e. the information or support requested were received. Each user’s intent as coded by researchers together with its linked text were copied into an excel dataset. The dataset allowed researchers to systematically compare intents and judging whether or not they were met by replies.

- As a result, the internal validity of the study may be questionable. If within the study design, participants were followed up by a survey study to verify their identities and results, then the evidence of this study would be much stronger.

We have described above the analysis process to support of the internal validity of the results. The online forum was hosted from the Stroke Association website, with the intent to “share stories and experiences, find out what has worked for others and provide each other with support and information”, as stated at https://www.stroke.org.uk/forum. We have no reason to believe that a significant proportion of users falsified information, although acknowledge the lack of verification of participants identity as a limitation of the study, page 3, line 58-59: The analysis of the forum was limited by the time users were active in the forum, by the form moderation process, and by the lack of assessment of the authenticity of the forum content.

- There are some statements need clarification. It is interesting to see participants within the age range of 0 to 10 years on the online discussion forum. Is the ‘age’ self-reported or all the participants have to register with date of birth? That is, if participants failed to report their true age, then suffering a stroke at age 0 could be the case. Please elaborate.

Information about age and age at stroke were self-reported, as the Stroke Association has not handed over user profiles. We have reported this at page 5, lines 102-104: To maintain anonymity and protect confidentiality, user profiles were not included (see box 1). Information on the user population was extracted by reading subsequent posts of each user. To clarify this further we have added text in the methods, page 5, line 109-111: Username, sex, age at stroke, age at time of posting, time since stroke, whether participant was a survivor or a patient discussed by third party, third party relation with patient (e.g. son, daughter, sister etc) and number of posts/participants were retrieved where available within the posts.

We have also added 2 supplementary figures to clarify the relationship between age at stroke and whether participants were survivors or patients talked about by third party. We have added the following paragraphs, page 8, lines 194-196: The forum included participants who suffered with stroke during the first 5 years of life (see figure 2), of which the majority were patients talked about by third party (see online supplementary figure S1a-d, in particular S1d); page 9, lines 219-221: Most children with stroke were patients talked about by third party (see online supplementary figure S2a-d, in particular S2c and S2d. It is these children that are the participants in the 0-10 age group. If an age was not available, it was coded as missing.

• There are some concerns about some statements or inferences in this paper. For example, since this is an online forum study, “producing a sample of participants that were representative of the sex and ages at stroke” as mentioned in the paper, may be compromised.

We have corrected the statement, which was referring to a sample of participants representative of the forum population, rather than the general population of patients with stroke in the UK, see page 6, lines 128-129: In order to produce a sample of participants that were representative of the forum population according to sex and ages at stroke.

• On page 8, in the statement of “the population of survivors and of patients described by third party had near normal distributions, spanning all ages”, normal distributions is a strong statistical statement.
We have added the supplementary figure S1 to better illustrate the distribution of the age at stroke of
the entire forum population and more specifically the populations of participants who are stroke
survivors and patients who are talked about by third party. We have also added supplementary figure
S2 to further describe participants’ distributions according to sex and age at stroke, and the
comparison with SNAPP data.

• Based on the age distribution, participants were not as “young” as mentioned on page 12
(implications for clinicians and future research) as there were many participants aged 60 to 95.

There were indeed several patients aged between 60 and 95, and we feel that the 2 supplementary
figures S1 and S2 allow better quantification of the older population, whether survivors or patients
talked about by third parties.

• In the abstract, the conclusion was that “patients’ needs expressed in the online forum confirm and
widen the evidence…showing that such forums are a potential resource for studying needs in this
population.” However, it seems to me that this study was not to confirm that the online forum is a
great resource (not verified), but to provide the thematic analysis and categories the online topics that
stroke survivors and their associates discussed more often than other topics.

This study had 3 aims: the first was to provide descriptive analysis of the participants in the online
forum, the second was to describe the reasons for posting in the forum and the last one was to
describe whether responses addressed users’ needs, as stated in the abstract, page 2, line 27-28:
Objective: To describe the characteristics of participants of an online stroke forum, their reasons for
posting in the forum and whether responses addressed users’ needs. We have added 2
supplementary figures to substantiate further the descriptive analysis of the population of forum
participants. How the 3 aims were addressed in this study is reflected in the opening of the discussion
at page 10, lines 268-277: This study shows that stroke survivors of both sexes and across a range of
ages, stroke type and disabilities were active users of an online forum, although generally
representing a younger population than those admitted to hospital. Survivors and third parties were
together taking part in the discussions. Severe disability did not preclude access to the forum. The
forum was mainly used as a mean to ask and receive information and support and sharing one’s own
story of stroke. The great majority of users’ intents were met by the replies received and a wide
variety of topics were discussed. Information and support were provided on an individual basis and
contextualised with personal experiences from both requesting and replying users. Online forums for
patients with stroke represent a potential resource for studying unmet needs in this population,
complementing the evidence from traditional research studies, as shown in a sister paper.41 The
reference to another paper currently in consideration by BMJ Open has been added (reference n. 41).

• It is not clear why the first two participants per group were selected for further thematic analysis.

We selected the first 2 participants per group according to alphabetical order as a mean to avoid
selection bias.

Minor recommendation
• Page 2, Abstract: suggest removing the sentence “although younger than the UK stroke population
(mean age 52 years vs 77 years in SSNAP)”

The distribution of age at stroke of forum participants was compared with the distribution of age at
stroke from SSNAP. Despite many forum participants being aged 65-90, the age at stroke distribution
of forum participants was centred on 52 years, i.e. a younger age compared with SSNAP (77 years).
We have therefore opted not to remove the sentence. We have added two supplementary figures to
better describe the study participants' population. The figures allow better evaluation of prevalence of age at stroke ranges.

• Page 4, Introduction, line 19: the citation should take place after the comma (i.e., ,23). Similar things occurred on line 54.

Thank you, we have corrected this.

• Page 8, line 2: 1,391 instead of 1391 to be consistent across the paper.

Thank you, we have corrected this.

• Page 8, line 51: suggest replacing “P<0.0001” to “P<0.001”

Thank you, we have corrected this.

• Re-arrange the sequences of tables and figures.

References to tables and figures have been added throughout the results making rearranging tables and figures unnecessary.

• Bibliography: Extra space after reference#9, and extra doi information with reference#10.

Thank you, we have corrected this.

Reviewer: 2
Please leave your comments for the authors below

Overall the paper is well written. My recommendation is to accept the paper with minor revisions to address the points set out below:

Abstract:
Overall the abstract is clear and well written. The objective of the study is clear.
• In the conclusions section the authors could specify what specific advice and support such an online forum enables patients and families to give and receive.

The specific advice that online forum enables patients and families to give and receive is described in the abstract (Results section) at page 2, lines 44-45: Most information needs were around stroke related physical impairments, understanding the cause of stroke and the potential for recovery.
We have specified the support provided by the online forum in the abstract Conclusions at page 2, lines 48-49: The forum provided an opportunity for patients and families to give and receive advice and social support from other users.

• Introduction:
The authors could make a better link between the first and second sentences- unmet needs of stroke survivors and higher levels of social support associated with improved health outcomes with people with stroke and other long term conditions.

To improve the link between first and second sentences we have added at page 4, lines 69-70: Therefore providing social support to patients can improve health outcomes after stroke.

• In the second paragraph, specifically in what ways do health professionals understand stroke differently compared to stroke survivors in the study of stroke groups cited?
We have added the following sentence at page 4, lines 75-76: (i.e. professionals were perceived as not adequately understanding stroke and how patients could cope with recovery).

• Methods:
The methods and process of quantitative and qualitative analysis are clear and well described.

Results:
Second paragraph on p.8, there seems to be a word missing from the second sentence.

The second sentence from the second paragraph at page 8, lines 190-191 now reads: Information about sex was retrievable in 91% (2,127) patients, while age at stroke and time since stroke was retrievable in 49% (1,154) and 40% (934), respectively.

• Under the subheading ‘Forum topics’ the topics identified refer to table 3, but reference to table 4 is missing.
Thank you for pointing this out. We have corrected the reference at page 10, line 251: 21 main topics were identified (table 4).

• Discussion:
In places the discussion is quite descriptive and requires further interpretation.
Specifically:
Could the authors comment more on the significance and implication of forum participants being younger compared to the overall stroke population (first paragraph on p.11) and of higher education (last paragraph on p.11), and that third party users participating in the forum represented patients in the first year post stroke and those with higher levels of disability (first paragraph on p.12).

We have added the following comments in the discussion at page 12, lines 291-292: This might be down to younger stroke survivors having more unmet needs of information and social participation and/or seeing an online forum as a resource for such needs.
At page 13, lines 327-330: Given that employment was not disclosed by the great majority of participants, it was not possible, though, to draw conclusions on how participants’ social classes compared with the overall population of patients with stroke.
At page 13, lines 337-339: This might be down to more unmet needs of information and support in the first period after stroke in both patients with severe disability and their families, and/or younger family members/carers considering online forum as potential source of advice.

• Under the implications section could the authors specify what similar issues participants taking part in the online forum raised compared to the wider stroke population (first sentence, second paragraph on p.12).

We have added the paragraphs at page 13, lines 342-344: Unmet needs were reported across a range of clinical domains, including mobility and communication, recovery potential, interaction with healthcare professionals, medicines and emotional well-being as well as need for information and aspects of social participation.
At Page 13, lines 346-348: A survey study to investigate unmet needs that included patients of older ages did not find differences in the range or type of unmet need reported by age category, suggesting that age per se may not be associated with perception of unmet need.
GENERAL COMMENTS
The manuscript is well written. Overall the authors have improved the paper and addressed the points I previously made. My recommendation is to accept the paper.

There are a few minor points/typographical errors to address:

Page 9, line 218: suggest adding ‘category’ or ‘age range’ after ‘0-20 year old’.

Page 10, line 256: suggest change ‘invisible ones’ to ‘invisible effects, such as…’ (and provide a few examples).

Page 11, line 263: suggest omitting the word ‘being’ before ‘experienced’.

Page 11, line 271: add an s after ‘mean’.

Page 12, line 292: can the authors add a reference here to support their claims that younger stroke survivors may have more unmet informational and social participation needs.

Page 12, line 293: consider changing ‘given away’ to ‘exchanged’.

Page 13, line 326: consider changing ‘down both to’ to ‘down to either’.

Page 14, line 358: suggest spelling out briefly the key features of an holistic definition of self-management as proposed by the Institute of Medicine.

VERSION 2 – AUTHOR RESPONSE
Reviewers comments
The manuscript is well written. Overall the authors have improved the paper and addressed the points I previously made. My recommendation is to accept the paper.

There are a few minor points/typographical errors to address:

Page 9, line 218: suggest adding ‘category’ or ‘age range’ after ‘0-20 year old’.
Response
Page 9, line 217 (marked document): ‘category’ has been added.

Page 10, line 256: suggest change ‘invisible ones’ to ‘invisible effects, such as…’ (and provide a few examples).
Response
Page 10, lines 253-254 (marked document): we have replaced ‘invisible ones’ with ‘invisible effects’ and added the following text: ‘invisible effects, such as fatigue, emotional lability, impaired self-confidence, and memory and cognitive problems’.
Page 11, line 263: suggest omitting the word ‘being’ before ‘experienced’.
Response
Page 10, line 261 (marked document): ‘being’ has been deleted.

Page 11, line 271: add an s after ‘mean’.
Response
Page 11, line 269 (marked document): the ‘s’ has been added to ‘mean’.

Page 12, line 292: can the authors add a reference here to support their claims that younger stroke survivors may have more unmet informational and social participation needs.
Response
Page 11, line 289-291 (marked document): reference 43 has been cited here.
The sentence has been slightly changed from ‘This might be down to younger stroke survivors having more unmet needs of information and social participation and/or considering an online forum as a resource for such needs’ to ‘This might be down to younger stroke survivors being more aware of what their unmet needs are and accessing an online forum as a resource for such needs’.

Page 12, line 293: consider changing ‘given away’ to ‘exchanged’.
Response
Page 11, line 292 (marked document): ‘given away’ has been replaced with ‘exchanged’.

Page 13, line 326: consider changing ‘down both to’ to ‘down to either’.
Response
Page 13, line 325 (marked document): ‘down both to’ has been replaced with ‘down to either’.

Page 14, line 358: suggest spelling out briefly the key features of an holistic definition of self-management as proposed by the Institute of Medicine.
Response
Page 14, line 358-360 (marked document): the holistic definition of self-management as proposed by the Institute of Medicine has been added: “the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions”
Stroke survivors and their families receive information and support on an individual basis from an online forum: descriptive analysis of a population of 2348 patients and qualitative study of a sample of participants

Anna De Simoni, Andrew Shanks, Chantal Balasooriya-Smeekens and Jonathan Mant

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- Research methods (619)

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Correction

De Simoni A, Shanks A, Balasooriya-Smeekens C, et al. Stroke survivors and their families receive information and support on an individual basis from an online forum: descriptive analysis of a population of 2348 patients and qualitative study of a sample of participants. BMJ Open 2016;6:e010501. In the last section of table 2 of this paper (‘Third party users’ – ‘Female carers’) the first number in the top left should read ‘473’ (not ‘73’).

BMJ Open 2016;6:e010501corr1. doi:10.1136/bmjopen-2015-010501corr1