

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder
AUTHORS	Jones, Susan; Hanchard, Nigel; Hamilton, Sharon; Rangan, Amar

VERSION 1 - REVIEW

REVIEWER	Margaret Staples PhD Biostatistician Department of Epidemiology and Preventive Medicine Monash University Cabrini Institute Australia No conflicts of interest to declare.
REVIEW RETURNED	30-Jul-2013

THE STUDY	<p>Patients appear to have been drawn from a single community medical practice (GP clinic?) as well as from specialist clinics where the authors also worked. It is unclear how representative these patients would be of the general FS patient. Those from the GP clinic would perhaps be representative but patients from specialist clinics may differ from community patients in things such as pain, function and access to medical care. No information is given regarding the response rate, e.g., how many information packs were handed out to obtain the sample of 11 participants.</p> <p>A sample size of around 20 is usually required to reach data saturation so was recruitment of sufficient participants difficult?</p> <p>The authors say purposive sampling was employed to obtain a sample representative of FS patients. No information is given about any 'responders' to the initial information who may have been excluded because they had characteristics that were already represented in the sample.</p> <p>My other concern is the small sample size (noted by the authors) that precluded data saturation. This, combined with the lack of information about participants (e.g., average duration of symptoms for each of the groups and the whole sample), limits the usefulness of the results.</p> <p>It would also be helpful to know the relative prevalence of primary and secondary FS.</p> <p>This is a qualitative study so specific outcome measures are not applicable but could be interpreted as finding common themes.</p>
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	I cannot comment on the references as FS is not my specific area of expertise.
RESULTS & CONCLUSIONS	<p>The 'No' responses above indicate that the answers to the questions are 'Unclear'.</p> <p>The research question was to 'elucidate patients' perceptions of, and treatment priorities for, FS'. Given that data saturation was not achieved and it is difficult to determine if the sample is representative, it is unclear whether the results answer this question, are credible or the interpretations and conclusions are warranted.</p>
GENERAL COMMENTS	Inclusion of more details about recruitment and participant selection would assist with interpretation of the results.

REVIEWER	<p>Tim Rapley Lecturer in Medical Sociology Institute of Health and Society, Newcastle University UK</p>
REVIEW RETURNED	02-Aug-2013

THE STUDY	<p>In relation to statistical methods question - this is not relevant</p> <p>There is one clear omission in the literature, which albeit briefly, discusses patients experiences of frozen shoulder, through qualitative interviews.</p> <p>Carter B. Clients' experiences of Frozen Shoulder and its treatment with Bowen technique. Complementary Therapies in Nursing and Midwifery. 2002;8(4):204–210</p> <p>Clearly, given the claims in the paper, that the submitted paper is the first to investigate patients experiences this need to be modified.</p>
RESULTS & CONCLUSIONS	See above, they just need to relate their (much more substantive) findings to the prior paper that discusses patients experience of frozen shoulder. Also, I think they need to relate, albeit briefly, to the other literature that relates to some of the factors/themes they explore. So, for example, they discuss delay in diagnosis - which echoes experiences of a range of patient groups (most work has focused on cancer - but the same issues emerge). Also, they discuss inconvenience/disability - again, this echoes (or has family resemblance) to how people adjust to an illness (again - echoes to lots of the chronic illness literature - especially the work that emerged around biographical disruption).
GENERAL COMMENTS	<p>Overall, this is nice. All my comments are relatively minor.</p> <p>Page 1: I actually prefer the description that you give about in the 'article focus' section to the one you give in 'objectives' (which does not flow as well)</p> <p>Page 2: You discuss recall bias – in relation to time from treatment? Diagnosis? Recovery? We need some sense – both here and later – about what kind of time frames we are working with. Also, is recall bias really the central issue here – these are all interviews – surely, if we talk in such terms, we could also talk about terms of response bias – so morality etc ... I'm, just not quite sure what you gain by</p>

	<p>talking in the language of recall bias.</p> <p>Page 3: Is the phrase 'adherence' the right one, given the focus on 'concordance' these days?</p> <p>Page 4: I'm not sure, in this context, that you need to talk about your sample being representative (especially given n=12). Surely, you could talk the language of (types of) purposive sampling – so in your case, following Patton, this is either – a 'structured purposive sample', structured along the lines of 'phase' (which seems the best description, albeit within this you've got other factors, like age) – or a combination of both 'structured' and 'variation' within that.</p> <p>Page 4 – Clearly there are both positive and negative issues raised by not being directly involved in FS management – so I'm not sure I'd stress that this somehow enable objectivity per se – objectivity (or rather, some version of neutralism) is enacted, it is not given per se – as you could lose the subtly, nuances etc that comes from knowledge of the practice.</p> <p>Page 5: In relation to participants – could you not offer the reader a table – as this would more easily enable them to see, at glance, the key issue. Also, as raised above, it would be nice to understand – for each case – how long before they sought help from a medical professional, how long until they got an accurate diagnosis, how long until they got treatment and how long the problem lasted for until 'recovery' (this would also help put some context on the comments in thee 3 around delay, difficulty and disappointment)</p> <p>Page 5 – how do you define 'significant delay' – (so, what would a good referral pathway time look like)</p> <p>Page 6: I'm not sure the order of your themes works. I'd be tempted to put 'Awareness and expectations' before inconvenience.</p> <p>Page 6: I'm not sure the long list of ADL is needed, a few examples could be enough.</p> <p>Page 6: The comment about 'few outward signs' and the quote offer related but different readings. Clearly, this is not visible per se, but action might orientate others to ask questions about the problem. And secondly, as the quote seems to focus more on, if you tell someone you have frozen shoulder, this could be orientated to as 'shoulder pain' per se, as in, 'made everyday', and something that others have experienced, or have access to via their own experiences of shoulder pain and so evoke less understanding of the lived pain. In this way, this is hidden in two ways, one, at times, from a glance, but also the pain is hidden from other experiential lexicon of knowledge.</p> <p>Page 9 – As mentioned above, you need to relate your work/findings to both the 2002 paper I found – which briefly outlines, in the first section of results, similar issues to your work (which actually took a very quick search – so I'm not sure how it was missed in the HTA report) alongside a brief engagement with the broader literature on delay in diagnosis and experiences of illness etc.</p> <p>Page 10: I 'm really not sure I go with the idea that things like INVOLVE that patients perspectives where lacking in what you call the 'general clinical research agenda'. Social scientists working in</p>
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	medical schools have routinely been publishing in (general and condition/specialty- specific) medical journals on a range of aspects of patient experience.
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VERSION 1 – AUTHOR RESPONSE

Reviewer: Margaret Staples PhD
 Biostatistician
 Department of Epidemiology and Preventive Medicine
 Monash University
 Cabrini Institute
 Australia

No conflicts of interest to declare.

Patients appear to have been drawn from a single community medical practice (GP clinic?) as well as from specialist clinics where the authors also worked. It is unclear how representative these patients would be of the general FS patient. Those from the GP clinic would perhaps be representative but patients from specialist clinics may differ from community patients in things such as pain, function and access to medical care. No information is given regarding the response rate, e.g., how many information packs were handed out to obtain the sample of 11 participants.

Thank you. We have now provided more information about the participants in a table. We were not seeking “representativeness” in its technical sense: we have therefore clarified our approach (structured purposive sampling) in “Sampling”, and removed references to representativeness throughout. We have now specified the response rate.

A sample size of around 20 is usually required to reach data saturation so was recruitment of sufficient participants difficult?

We did experience some difficulties in recruitment, and have now expanded on these under “Strengths and weaknesses of the study”. As previously noted, “data saturation was not achieved”; but the key issue, in our view, is that there was sufficient repetition of the themes to instil confidence in them. We have therefore modified the text accordingly.

The authors say purposive sampling was employed to obtain a sample representative of FS patients. No information is given about any 'responders' to the initial information who may have been excluded because they had characteristics that were already represented in the sample.

We did not exclude any potential participants, and we have now specified this in “Sampling”. In the same section, although we have removed references to “representativeness”, we have now clarified that, “the demographic characteristics of the sample were consistent with the FS population in the UK at large”.

My other concern is the small sample size (noted by the authors) that precluded data saturation. This, combined with the lack of information about about participants (e.g., average duration of symptoms for each of the groups and the whole sample), limits the usefulness of the results.

Please see our previous comments about data saturation and the inclusion of a table.

It would also be helpful to know the relative prevalence of primary and secondary FS.

We have thoroughly revised the second paragraph of “Introduction” to improve clarity and, as far as possible (within the limitations of the published literature), to answer this point. We think that the revision better contextualises primary FS.

This is a qualitative study so specific outcome measures are not applicable but could be interpreted

as finding common themes.

Thank you. We agree that specific outcome measures are inapplicable to this qualitative study, and that the link between outcomes and identifications of themes is somewhat tenuous. We would therefore prefer not to activate this heading.

I cannot comment on the references as FS is not my specific area of expertise.

The research question was to 'elucidate patients' perceptions of, and treatment priorities for, FS'. Given that data saturation was not achieved and it is difficult to determine if the sample is representative, it is unclear whether the results answer this question, are credible or the interpretations and conclusions are warranted.
 Please see responses above.

Inclusion of more details about recruitment and participant selection would assist with interpretation of the results.
 Please see responses above.

Reviewer: Tim Rapley
 Lecturer in Medical Sociology
 Institute of Health and Society,
 Newcastle University
 UK

There is one clear omission in the literature, which albeit briefly, discusses patients experiences of frozen shoulder, through qualitative interviews.

Carter B. Clients' experiences of Frozen Shoulder and its treatment with Bowen technique.

Complementary Therapies in Nursing and Midwifery. 2002;8(4):204–210

Thank you for this comment. We were aware of this paper, and had included it in an earlier draft of this article; but subsequently excluded it as insufficiently relevant (it relates to non-conventional therapy). The HTA report to which we referred had excluded it for the same reason. On reflection, we agree that it is better included.

See above, they just need to relate their (much more substantive) findings to the prior paper that discusses patients experience of frozen shoulder. Also, I think they need to relate, albeit briefly, to the other literature that relates to some of the factors/themes they explore. So, for example, they discuss delay in diagnosis - which echoes experiences of a range of patient groups (most work has focused on cancer - but the same issues emerge). Also, they discuss inconvenience/disability - again, this echoes (or has family resemblance) to how people adjust to an illness (again - echoes to lots of the chronic illness literature - especially the work that emerged around biographical disruption).
 Text amended as suggested.

Clearly, given the claims in the paper, that the submitted paper is the first to investigate patients experiences this need to be modified.

Text amended as suggested.

Overall, this is nice. All my comments are relatively minor.

Page 1: I actually prefer the description that you give about in the 'article focus' section to the one you give in 'objectives' (which does not flow as well)
 Objectives now read the same as the article focus.

Page 2: You discuss recall bias – in relation to time from treatment? Diagnosis? Recovery? We need some sense – both here and later – about what kind of time frames we are working with. Also, is recall bias really the central issue here – these are all interviews – surely, if we talk in such terms, we could also talk about terms of response bias – so morality etc I'm, just not quite sure what you

gain by talking in the language of recall bias.

Thank you for this comment. We have replaced “bias” by “error”, which better reflects our intended meaning. The description in the “Participants” paragraph and the new table aim to convey the sense that, in some cases, participants’ retold experiences spanned years.

Page 3: Is the phrase ‘adherence’ the right one, given the focus on ‘concordance’ these days?
 Amended.

Page 4: I’m not sure, in this context, that you need to talk about your sample being representative (especially given n=12). Surely, you could talk the language of (types of) purposive sampling – so in your case, following Patton, this is either – a ‘structured purposive sample’, structured along the lines of ‘phase’ (which seems the best description, albeit within this you’ve got other factors, like age) – or a combination of both ‘structured’ and ‘variation’ within that.

We agree. We have removed references to representativeness and moved towards referring to consistency of demographic of populations. We have also strengthened the language on structured purposive sampling and included a reference to Patton 2002.

Page 4 – Clearly there are both positive and negative issues raised by not being directly involved in FS management – so I’m not sure I’d stress that this somehow enable objectivity per se – objectivity (or rather, some version of neutralism) is enacted, it is not given per se – as you could lose the subtly, nuances etc that comes from knowledge of the practice.

Thank you for these helpful insights. We have removed the phrase in question.

Page 5: In relation to participants – could you not offer the reader a table – as this would more easily enable them to see, at glance, the key issue. Also, as raised above, it would be nice to understand – for each case – how long before they sought help from a medical professional, how long until they got an accurate diagnosis, how long until they got treatment and how long the problem lasted for until ‘recovery’ (this would also help put some context on the comments in thee 3 around delay, difficulty and disappointment)

We agree that the table makes a big contribution to clarity, thank you. We were unable to record the duration of the condition, however, as participants had not necessarily recovered by the end of the study.

Page 5 – how do you define ‘significant delay’ – (so, what would a good referral pathway time look like)

We have removed the word ‘significant’. Features of a good care pathway are found in the implications section.

Page 6: I’m not sure the order of your themes works. I’d be tempted to put ‘Awareness and expectations’ before inconvenience.

We agree. Amended.

Page 6: I’m not sure the long list of ADL is needed, a few examples could be enough.

We would prefer not to alter this text. Our paper is aimed at clinicians who treat FS. Although they think they know which aspects of life are affected by FS, we are sure they will be surprised by many items on the list, and at how disruptive such a seemingly non-serious condition can be. We hope that this will sway their whole approach to people with this condition. In the future these items may suggest appropriate outcome measures of treatment, as compared with the standard list of ADLs or other clinically based measures.

Page 6: The comment about ‘few outward signs’ and the quote offer related but different readings. Clearly, this is not visible per se, but action might orientate others to ask questions about the problem.

And secondly, as the quote seems to focus more on, if you tell someone you have frozen shoulder, this could be orientated to as 'shoulder pain' per se, as in, 'made everyday', and something that others have experienced, or have access to via their own experiences of shoulder pain and so evoke less understanding of the lived pain. In this way, this is hidden in two ways, one, at times, from a glance, but also the pain is hidden from other experiential lexicon of knowledge. The two aspects of hidden suffering have now been made explicit and a supporting quote added.

Page 9 – As mentioned above, you need to relate your work/findings to both the 2002 paper I found – which briefly outlines, in the first section of results, similar issues to your work (which actually took a very quick search – so I'm not sure how it was missed in the HTA report) alongside a brief engagement with the broader literature on delay in diagnosis and experiences of illness etc. See comment to first reviewer. The HTA report focused on conservative, conventional and standard interventions; therefore Carter (2002) which reported on an alternative therapy was excluded.

Page 10: I 'm really not sure I go with the idea that things like INVOLVE that patients perspectives where lacking in what you call the 'general clinical research agenda'. Social scientists working in medical schools have routinely been publishing in (general and condition/specialty- specific) medical journals on a range of aspects of patient experience. We have amended the text to clarify that we are only referring to research into FS, not patient experience as a whole.

VERSION 2 – REVIEW

REVIEWER	Dr Margaret Staples Biostatistician Monash University Department of Epidemiology and Preventive Medicine Department of Clinical Epidemiology, Cabrini Hospital Australia
REVIEW RETURNED	23-Aug-2013
THE STUDY	The authors have adequately addressed my concerns and the manuscript is now substantially clearer.
REPORTING & ETHICS	There does not appear to be a statement in the paper regarding ethical approval for the study. Was approval obtained?