

## PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Coping in the role as next of kin of a person with a brain tumor: a qualitative metasynthesis
<b>AUTHORS</b>	Lien, Anette; Rohde, Gudrun

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Jenny Drott Linköping University
<b>REVIEW RETURNED</b>	17-Aug-2021

<b>GENERAL COMMENTS</b>	<p>Dear Author, Thank you for a interesting study with a important topic.</p> <p>Here are some reflections and comments;</p> <p>Title Overall a good and clear title but may be enough to write only coping.</p> <p>Abstract Overall clear and balanced. Keywords: it is enough with coping? Include “qualitative research/studies”?</p> <p>Introduction Page 3, line 55; Why data from 2018? It is possible to include data/numbers from 2020? Why include data from Norway, when the purpose of the study was to investigate all international qualitative studies/research? Do you have more references than 3+4 due to symptom burden and symptoms? My recommendation is to add newer and replace reference 4 with any “heavier” reference. Page 4, line 76- It is reference 12 relevant to the claim/sentence? Page 4, line 76-77- “There is some quantitative research” .... Please include the references, and the sentence “more complementary and personal” is hard to understand, revise? From my point of view, coping is central in the study. And Lazarus and Folkman are only short in the end of the introduction. Maybe this important topic is a heading in the introduction (theoretical view/perspective/frame) and highlights early in the introduction.</p> <p>Methods Overall clear and easy to follow, some small issues, Page 4, line 88- it is original studies instead of primary? Page 6, line 114- Nordic language? Clarify Page 7, line 147- Please clarify “The most poorly addressed....” Page 8, heading Synthesis- add the whole names of the themes.</p>
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	<p><b>Results</b> Overall well-written and clear. There are quotes from some of the studies, how were these selected? There is an imbalance between themes, but they are written as "Main theme 1 and 2", or was theme 1 hierarchies over the other (which is less developed)?</p> <p><b>Discussion</b> See comments about the theoretical frame in the introduction, to make it more clear and strengthen the red thread through the manuscript. Page 17, line 361-362- Do you have subthemes? Or it is one main theme and one subtheme? Please see the comment about the result section.</p> <p>Table 1; Please be consistently in the table, see for example in type of tumor- between Arber and Cutillo. In Arber you only write Malignant, while in Cutillo you write 15 benign 25 malignant...</p>
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<b>REVIEWER</b>	Erin Forbes University of Newcastle, School of Medicine and Public Health
<b>REVIEW RETURNED</b>	22-Nov-2021

<b>GENERAL COMMENTS</b>	<p>Being the next of kin of a person with a brain tumor: a metasynthesis focusing on coping factors and strategies</p> <p><b>GENERAL</b> I would appreciate a more detailed explanation of the process that determined the classification of the subthemes. I found it confusing and unclear, with no clear difference why some are considered factors, while others are considered strategies. This is briefly discussed in the limitations section, however it needs to be address in the body of the paper, and a greater explanation provided.</p> <p><b>ABSTRACT</b> <b>Results</b> Page 2, line 25 – Wording is clunky. Separate the inclusion criteria (type of study and type of participants) into two separate sentences.  Page 2, line 29 “The next of kin rely on coping factors such as their personal characteristics, finding meaning in their situation...”. This sentence doesn’t read well. Personal characteristics aren’t something that people ‘rely on’. Consider rewording.</p> <p><b>Conclusions</b> Page 2, lines 33-35 The first sentence is very confusing.</p> <p><b>METHODS</b> <b>Search Strategy</b> Page 5 - The search strategy should be included as an appendix, not in the main body of text.  Page 6, line 116 – add a comma after the word ‘stage’ – tumors, regardless of tumor type and stage, that enhanced their role as next of kin.</p> <p><b>Search outcome</b></p>
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	<p>Page 6, line 123 – please include an explanation of what Rayyan is (e.g. systematic review management software etc, etc)</p> <p>Page 6, line 127 – The flow could be improved in this paragraph if the sentence that begins “A final consensus regarding the eligible articles...” was moved up to line 124, ahead of the sentence that describes the number that were ultimately included “19 of these were included in the metasyntesis”</p> <p>Patient and public involvement Page 8, Line 177 “primary studies and DOES not involve</p> <p>RESULTS Main theme 1 Generally, I feel that the themes are not well described, and could be spelled out clearer. Each subtheme seems brushed over, without thorough explanation for how that factor affects coping. Simple rewording could really improve the flow and readability.</p> <p>Main theme 2 Page 12, 264-266 – The description of regaining control is confusing. Being provided with enough information is not necessarily a proactive thing? Seeking out further information could be considered gaining control, but I am unclear why being given enough information is a coping strategy when it is outside the next of kin’s control (and in which case, I would assume this subtheme belongs in the ‘coping factors’ main theme)</p> <p>Page 13 line 282 - 288 – how are the next of kin fighting the disease? Does this mean encouraging their loved one to continue fighting? How does the next of kin adopting a healthier lifestyle improve the medical treatment? Is this referring to them facilitating this change for the patient? This is not clear.</p> <p>DISCUSSION Page 15, line 328-333 – Confusing wording, and seems unclear where this conclusion was</p>
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### VERSION 1 – AUTHOR RESPONSE

Comments from reviewer: 1

Title

Overall a good and clear title but may be enough to write only coping.

*Reply: We have discussed this, but would rather prefer to include both coping factors and strategies*

Abstract

Overall clear and balanced.

Keywords: it is enough with coping? Include “qualitative research/studies”?

*Reply: We have included the keyword **qualitative studies** as well*

Introduction

Page 3, line 55; Why data from 2018? It is possible to include data/numbers from 2020?

*Reply: Thank you for underlining this mistake, we have included updated numbers from 2020 which were the latest available, page 3, line 57.*

Why include data from Norway, when the purpose of the study was to investigate all international qualitative studies/research?

*Reply: We have deleted the data from Norway and just included international ones, page 3, line 57.*

Do you have more references than 3+4 due to symptom burden and symptoms? My recommendation is to add newer and replace reference 4 with any "heavier" reference.

Page 4, line 76- It is reference 12 relevant to the claim/sentence?

*Reply: We have included more references page 3, line 61, included a "heavier" references page 3, line 65 and deleted the previous reference 12.*

Page 4, line 76-77- "There is some quantitative research" .... Please include the references, and the sentence "more complementary and personal" is hard to understand, revise?

*Reply: We have included some references as examples page 4, line 87 and changed the sentence to "...personal and focused the lived experience of next of kin" page 4, line 87 and 88.*

From my point of view, coping is central in the study. And Lazarus and Folkman are only short in the end of the introduction. Maybe this important topic is a heading in the introduction (theoretical view/perspective/frame) and highlights early in the introduction.

*Reply: We have included the definition of coping by Lazarus and Folkman page 4, line 72-78, but not under a heading (theoretical view/perspective/frame), as our intention are not to confirm their theory. Because of changes in the introduction we have deleted some of the text in the discussion page 15, line 329-332.*

## Methods

Overall clear and easy to follow, some small issues, Page 4, line 88- it is original studies instead of primary?

*Reply: We have replaced primary studies with original studies, page 4, line 90. The word original has also been used throughout the manuscript. We would also like to mention that an updated literature research has been done.*

Page 6, line 114- Nordic language? Clarify Page 7, line 147- Please clarify "The most poorly addressed...."

*Reply: We have replaced Nordic language with: "original studies published in English, Norwegian, Swedish or Danish language" page 6, line 124 and 125. We have also clarified by including (criteria number 6 in the CASP list) page 7, line 160.*

Page 8, heading Synthesis- add the whole names of the themes.

*Reply: We have added the whole names of the themes page 9, line 186-187.*

## Results

Overall well-written and clear.

There are quotes from some of the studies, how were these selected?

*Reply: We have included the sentence: "Each subtheme is supported by illustrative quotes from the original studies included". Page 9, line 197-198 to elaborate on this.*

There is an imbalance between themes, but they are written as "Main theme 1 and 2", or was theme 1 hierarchies over the other (which is less developed)?

*Reply: We have tried to make this clearer by including the sentence: "The two main themes of this metasynthesis were coping factors within the next of kin and as external support and coping strategies – control and proactivity". Page 9, line 187-187. Furthermore, we have underlined that the main themes comprised sub themes. In the results the sub themes are now emphasized in italic throughout the text.*

## Discussion

See comments about the theoretical frame in the introduction, to make it more clear and strengthen the red thread through the manuscript.

*Reply: See reply given above*

Page 17, line 361-362- Do you have subthemes? Or it is one main theme and one subtheme? Please see the comment about the result section.

*Reply: We have included the explanation/text: ". ... and as a metasynthesis containing seven subthemes presented under two main themes. Each subtheme is supported by illustrative quotes from the original studies included" page 9, line 198-198 which hopefully makes this clearer.*

Table 1; Please be consistently in the table, see for example in type of tumor- between Arber and Cutillo. In Arber you only write Malignant, while in Cutillo you write 15 benign 25 malignant.

*Reply: Thank you for pointing this out. Some of the studies don't provide the readers with the type of tumor. These studies have been marked with a \* in the table to explain that this is missing.*

Reviewer: 2

## GENERAL

I would appreciate a more detailed explanation of the process that determined the classification of the subthemes. I found it confusing and unclear, with no clear difference why some are considered

factors, while others are considered strategies. This is briefly discussed in the limitations section, however it needs to be address in the body of the paper, and a greater explanation provided.

*Reply: We have hopefully determined the classification of the subthemes by including the sentence “The two main themes of this metasynthesis were coping factors within the next of kin and as external support and coping strategies – control and proactivity. The first main theme, coping factors, consisted of the subthemes, personal characteristics, meaningful external support, having interlocutors, and hope and religion. The second main theme, coping strategies, consisted of the subthemes regain control, fight against, and acceptance”. Page 9, line 185-191 and “... metasynthesis containing seven subthemes presented under two main themes. Each subtheme is supported by illustrative quotes from the original studies included” page 196-198, line 9. Throughout the result-section we have also emphasized the sub themes in italic.*

*In the introduction we have included the definition by: “Lazarus and Folkman define coping as a cognitive and behavioral endeavor under constant change, dealing with external and/or internal demands that a cognitive assessment indicates are stressful or that exceed personal resources. When dealing with these demands, the next of kin has to review available coping **resources**; personal, external and characteristics of the situation itself. This review will determine whether the situation is perceived as manageable or stressful, and secondly influence which coping strategy next of kin use” page 4, line 72-79. We hope that these changes have made it less confusing and unclear*

## ABSTRACT

### Results

Page 2, line 25 – Wording is clunky. Separate the inclusion criteria (type of study and type of participants) into two separate sentences.

*Reply: In accordance with the reviewer’s suggestions, we have re-written the text: “Inclusion criteria were qualitative original studies focusing on coping factors or strategies used by the next of persons with brain tumors. The study participants had to be aged 18 years of age or older” page 2, line 24-27.*

Page 2, line 29 “The next of kin rely on coping factors such as their personal characteristics, finding meaning in their situation...”. This sentence doesn’t read well. Personal characteristics aren’t something that people ‘rely on’. Consider rewording.

*Reply: We have reworded the sentence to read: “The next of kin used coping factors such as their personal characteristics, finding meaning in their situation, external support, hope and religion, and having someone to talk to. Coping strategies to manage the situation involved, regaining control, being proactive, and acceptance”. Page 2, line 30-33*

### Conclusions

Page 2, lines 33-35 The first sentence is very confusing.

*Reply: We have rewritten the first sentence to; “Next of kin of patients with brain tumor used coping factors and coping strategies gathered within themselves, in their surroundings and with assistance from a higher power to handle the situation and their role”, page 1, line 34-37.*

## METHODS

### Search Strategy

Page 5 - The search strategy should be included as an appendix, not in the main body of text.

*Reply: The search strategy is now in an appendix*

Page 6, line 116 – add a comma after the word ‘stage’ – tumors, regardless of tumor type and stage, that enhanced their role as next of kin.

*Reply: The comma has been included in accordance with the reviewer’s suggestion*

### Search outcome

Page 6, line 123 – please include an explanation of what Rayyan is (e.g. systematic review management software etc, etc)

*Reply: We have included an explanation of what Rayyan is, page 6, line 134.*

Page 6, line 127 – The flow could be improved in this paragraph if the sentence that begins “A final consensus regarding the eligible articles...” was moved up to line 124, ahead of the sentence that describes the number that were ultimately included “19 of these were included in the metasynthesis”

*Reply: The sentence has been moved in accordance with the reviewer’s suggestion.*

### Patient and public involvement

Page 8, Line 177 “primary studies and DOES not involve

*Reply: We have included the word as suggested by the reviewer page 9, line 193*

## RESULTS

### Main theme 1

Generally, I feel that the themes are not well described, and could be spelled out clearer. Each subtheme seems brushed over, without thorough explanation for how that factor affects coping. Simple rewording could really improve the flow and readability.

*Reply: We have spell out the themes more and reworded the text throughout the results. Hopefully the flow and readability have been better.*

### Main theme 2

Page 12, 264-266 – The description of regaining control is confusing. Being provided with enough information is not necessarily a proactive thing? Seeking out further information could be considered gaining control, but I am unclear why being given enough information is a coping strategy when it is

outside the next of kin's control (and in which case, I would assume this subtheme belongs in the 'coping factors' main theme)

*Reply: We realize we have done a spelling mistake in this paragraph, for that we do apologize. We have now changed the text to make this clearer:" ..... , and for most this included gathering enough information to allow an overview of what to expect, which implied some form of security.*<sup>10 20-23 27 30 35 37</sup>

**"Quotation"**

*The information gathered and provided should preferably be adapted to the situation and the disease trajectory, and been given by health-care professionals" page 13-14, line 289-297.*

Page 13 line 282 - 288 – how are the next of kin fighting the disease? Does this mean encouraging their loved one to continue fighting? How does the next of kin adopting a healthier lifestyle improve the medical treatment? Is this referring to them facilitating this change for the patient? This is not clear.

*Reply: We have added the words facilitate and encouraging to make this clearer, and elaborated the text: "Being proactive facilitate and encouraging the patient to fight the disease were also important coping strategies, as it felt better than not doing anything and accepting the morbid situation" Page 14, line 307-309.*

**DISCUSSION**

Page 15, line 328-333 – Confusing wording, and seems unclear where this conclusion was

*Reply: We have edited these lines to: "An explanation for the next of kins experience of unmet needs might be lack of knowledge among health-care providers about how to assist in due course This may indicate that in some cases health-care providers should pay more attention to offer support in line with individual needs of the next of kin and for the care situations". Page 16-17, line 357-361.*

**VERSION 2 – REVIEW**

<b>REVIEWER</b>	Jenny Drott Linköping University
<b>REVIEW RETURNED</b>	12-Feb-2022

<b>GENERAL COMMENTS</b>	Dear Author,  All queries are resolved. Thank you for the opportunity to review the manuscript.
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<b>REVIEWER</b>	Erin Forbes University of Newcastle, School of Medicine and Public Health
<b>REVIEW RETURNED</b>	23-Feb-2022

<b>GENERAL COMMENTS</b>	Manuscript bmjopen-2021-052872.R1
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	<p><b>ABSTRACT</b> Conclusion Line 34 – “with assistance from a higher power”. I think this requires clarification that it is the belief that there is assistance from a higher power.</p> <p><b>OVERALL</b> The authors have made some improvements to the manuscript; however, I feel that there is still a lot of clarity needed regarding the themes and subthemes. There is no clear explanation of the difference between the two main themes ‘coping factors’ and ‘coping strategies’. It is also very unclear why some of the subthemes belong to one main theme over the other. For example, ‘Interlocutors’ could be seen as a proactive action (talking to people), and seems as though it should be included as a strategy. ‘Hope and Religion’ and ‘finding meaning in the situation’ also seem more like strategies than inherent ‘factors’.</p> <p>The aims of the study are also unclear – there are several different explanations of the purpose/aim:</p> <ol style="list-style-type: none"> <li>1. The aim was to identify and synthesize qualitative original studies that explored next of kin attitudes and experiences (methods, design)</li> <li>2. The purpose of this metasynthesis was to identify and synthesise evidence from original qualitative studies regarding the experience of next of kin with coping factors and strategies in their role as next of kin for a person with a brain tumor (introduction)</li> <li>3. This review will determine whether the situation is perceived as manageable or stressful, and secondly influence which coping strategy next of kin use (introduction).</li> </ol> <p>While similar, these descriptions of the purpose/aim are all different and do not provide the reader with a clear understanding of what the authors set out to do. The aim (as described in the abstract and introduction) is also the same as the main themes that were identified, which is suspicious. Were the two ‘main themes’ pre-determined before the data was synthesised? In which case this would be poor rigour.</p> <p>In the last paragraph of the introduction, the authors state that there are only a ‘few’ original qualitative studies that have investigated coping factors that make everyday life more manageable or which strategies next of kin use to cope with their new role and tasks. ‘A few’ is 3, which is very different to 20.</p>
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**VERSION 2 – AUTHOR RESPONSE**

Reviewer 2:

**ABSTRACT**

Conclusion

Line 34 – “with assistance from a higher power”. I think this requires clarification that it is the belief that there is assistance from a higher power.

*Reply: We have chosen to delete this in the conclusion*

## OVERALL

The authors have made some improvements to the manuscript; however, I feel that there is still a lot of clarity needed regarding the themes and subthemes. There is no clear explanation of the difference between the two main themes 'coping factors' and 'coping strategies'. It is also very unclear why some of the subthemes belong to one main theme over the other. For example, 'Interlocutors' could be seen as a proactive action (talking to people), and seems as though it should be included as a strategy. 'Hope and Religion' and 'finding meaning in the situation' also seem more like strategies than inherent 'factors'.

*Reply: We have tried to make this clearer throughout the manuscript by changes in the abstract (page 1-2, line 21-22 and 31-34), by including clarification in the introduction about what is meant by coping factors and coping strategies (page 4, line 70-77). In the method section, we have given a more comprehensive description of the analysis by adding: "In our metasynthesis we identified two main themes: 1. coping factors within the next of kin and as external support and 2) coping strategies – taking control and proactivity, each comprising 3-5 sub themes. For a list of the studies that generated findings for the main themes and subthemes, see Table 2. When analyzing and organizing the results into themes and subthemes we chose to be in line with the content and meaning of coping the included studies, although some of them could have been considered to also contributed and organized differently. The results will be elaborated below." (page 7, line 158-167). To more clearly show the organization of the main themes and subthemes, we have chosen to move the organization of the main themes and subthemes from the method section to the results (main theme 1 page 9, line 185-190, main theme 2, page 13, line 266-268). Finally, we have added more to the discussion about limitations of the organization into the different themes and subthemes (page 17, line 364-370)*

The aims of the study are also unclear – there are several different explanations of the purpose/aim:

1. The aim was to identify and synthesize qualitative original studies that explored next of kin attitudes and experiences (methods, design)
2. The purpose of this metasynthesis was to identify and synthesize evidence from original qualitative studies regarding the experience of next of kin with coping factors and strategies in their role as next of kin for a person with a brain tumor (introduction)
3. This review will determine whether the situation is perceived as manageable or stressful, and secondly influence which coping strategy next of kin use (introduction).

While similar, these descriptions of the purpose/aim are all different and do not provide the reader with a clear understanding of what the authors set out to do. The aim (as described in the abstract and introduction) is also the same as the main themes that were identified, which is suspicious. Were

the two 'main themes' pre-determined before the data was synthesised? In which case this would be poor rigour.

*Reply: Thank you for the comment, we have now chosen to use "The purpose of this study was to identify and synthesize qualitative original studies that explored coping in the role as next of kin of a persons with brain tumor" throughout the manuscript.*

In the last paragraph of the introduction, the authors state that there are only a 'few' original qualitative studies that have investigated coping factors that make everyday life more manageable or which strategies next of kin use to cope with their new role and tasks. 'A few' is 3, which is very different to 20.

*Reply: Thank you for the comment, we have now changed it to some*

### VERSION 3 – REVIEW

<b>REVIEWER</b>	Erin Forbes University of Newcastle, School of Medicine and Public Health
<b>REVIEW RETURNED</b>	03-Jun-2022

<b>GENERAL COMMENTS</b>	<p>Manuscript bmjopen-2021-052872.R2</p> <p>The authors have made changes to the manuscript; however, I believe the themes and subthemes are still very unclear. While it is discussed in the limitations, I believe it needs to be clarified in the body of the results.</p> <p>Introduction</p> <p>1. Page 4, line 104-106. When dealing with these demands, the next of kin has to review available coping factors that could be able to making the situation more manageable; personal, external and characteristics of the situation itself.<sup>14</sup></p> <p>This sentence is confusing. Inherent factors are not something the next of kin would review? If they are reviewing them, they would be strategies.</p> <p>Metasynthesis</p> <p>Main theme 1: Coping factors within the next of kin and as external support</p> <p>Changing the wording of some of the sub-themes may provide some clarity.</p> <p>1. The subtheme 'meaningful' would be clearer as a 'factor' if it was relabelled to 'perceiving the role as meaningful'. Additionally, the subtheme 'external support' may be better framed as 'having a support system'. See below.</p> <p>Coping factors within the next of kin and as external support (see table 2). This main theme comprised the five sub themes: personal characteristics, meaningful (change to 'perceiving the role as meaningful'), external support (change to 'having a support system'), having interlocutors, and hope and religion.</p> <p>2. It is also unclear why 'having interlocutors' and 'external support' are separate subthemes. From the descriptions, they read much the</p>
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	<p>same and don't seem to warrant separating.</p> <p>Main theme 2: Coping strategies – control and proactivity  This theme needs work. At the beginning of this section is outlines three main subthese: regain control, fight against, and acceptance. However in the body of the text, there is a description of the 'regaining control' subtheme, then the following subtheme seems to be 'being proactive' based on the formatting, then there is no formatting to indicate the 'acceptance' subtheme.</p> <p>Additionally, it is unclear why 'acceptance' is a strategy. This seems more like a factor.</p> <p>General  There are quite a few grammatical errors throughout the papers.</p>
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### VERSION 3 – AUTHOR RESPONSE

#### Introduction

1. Page 4, line 104-106. When dealing with these demands, the next of kin has to review available coping factors that could be able to making the situation more manageable; personal, external and characteristics of the situation itself.<sup>14</sup>

This sentence is confusing. Inherent factors are not something the next of kin would review? If they are reviewing them, they would be strategies.

*Reply: We have chosen to re-write the sentence and delete part of it.*

#### Metasynthesis

Main theme 1: Coping factors within the next of kin and as external support

Changing the wording of some of the sub-themes may provide some clarity.

1. The subtheme 'meaningful' would be clearer as a 'factor' if it was relabelled to 'perceiving the role as meaningful'. Additionally, the subtheme 'external support' may be better framed as 'having a support system'. See below.

Coping factors within the next of kin and as external support (see table 2). This main theme comprised the five sub themes: personal characteristics, meaningful (change to 'perceiving the role as meaningful'), external support (change to 'having a support system'), having interlocutors, and hope and religion.

*Reply: We have chosen to re-write in accordance with the reviewer's suggestion*

2. It is also unclear why 'having interlocutors' and 'external support' are separate subthemes. From the descriptions, they read much the same and don't seem to warrant separating.

*Reply: We have chosen to include the sub theme "having interlocutors" under the sub (new) theme "Having a support system."*

Main theme 2: Coping strategies – control and proactivity

This theme needs work. At the beginning of this section is outlines three main subthese: regain control, fight against, and acceptance. However in the body of the text, there is a description of the 'regaining control' subtheme, then the following subtheme seems to be 'being proactive' based on the formatting, then there is no formatting to indicate the 'acceptance' subtheme.

*Reply: We have re-written this and hopefully made it clearer, end of page 14 and beginning of 15. (line 305-312)*

Additionally, it is unclear why 'acceptance' is a strategy. This seems more like a factor.

*Reply: We have re-written the sub theme to emphasize why we consider it as a strategy, end of page 14 and beginning of 15. (line 305-312)*

General

There are quite a few grammatical errors throughout the papers.

*Reply: The paper has been edited by OnLineEnglish and a native speaking colleague.*