

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	The African, Caribbean, & European (ACE) Pathways to Care Study: A qualitative exploration of similarities and differences between African-, Caribbean-, and European-origin groups in pathways to care for psychosis.
AUTHORS	Ferrari, Manuela; Flora, Nina; Anderson, Kelly; Tuck, Andrew; Archie, Suzanne; Kidd, Sean; McKenzie, Kwame

VERSION 1 - REVIEW

REVIEWER	Vandad Sharifi Tehran University of Medical Sciences, Tehran, Iran
REVIEW RETURNED	24-Sep-2014

GENERAL COMMENTS	<p>This is a qualitative study to investigate different experiences of people with psychotic disorders coming from three ethnic groups. It was performed after another study in which the authors had found different DUPs across the ethnic groups. Their question is reasonable and deserves answer: Why is that and what are their experiences? However, I have major reservations about the paper.</p> <ol style="list-style-type: none">1. The main objectives of the study seems to be comparison between the experiences across different ethnic groups. However, this is not well reflected in the title of the paper, and on the other hand, most sections of the paper is devoted to the experiences of people regardless of their ethnicity.2. As I understand, subjects are distributed into different focus groups but its unclear how many groups are formed and how many subjects were in each group and how many sessions were held for each group. In addition, the sample size for focus groups are very small. Only 4 caribbean patients were enrolled in the groups and no African family member. That's not enough when the authors aim to examine differences across ethnic groups.3. It's not clear whether those in the groups are those with short or long DUPs especially when the authors are interested in exploring different experiences in ethnic groups.4. The main result of the study, according to the authors, is that internalization among the European is in the form of shame while among the minority groups is a guilt. However, the authors have not elaborated on that, nor in the results nor in the discussion section. Shame and guilt feelings are very related concepts. What are the main differentiating factor among these two feelings across the groups? Doing wrong is not the one that can best differentiate these two, at least to ordinary people. Is the guilt related to religious beliefs of people or anything to do with individualistic or collectivist attitudes? And what are the direct implications?5. What about the clinical status of patients? Apparently, the subjects were in stable phase and free from psychotic symptoms. But what about being depressed? Clinical or even subclinical
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	<p>depression may affect reporting shame and guilt feelings to a large extent.</p> <p>6. And finally the authors have claimed that these differences show how they affect ethnic groups' differing pathways to care and delays. But they didn't explain how these feelings and attitudes can lead to delays and how the anti-stigma campaigns and equitable services can address these differences.</p>
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REVIEWER	Terence McCann Victoria University, Melbourne, Australia
REVIEW RETURNED	26-Sep-2014

GENERAL COMMENTS	<p>Thank you for inviting me to review this manuscript titled 'The African, Caribbean, & European (ACE) Pathways to Care Study: How stigma operates in defining differences in pathways to care for psychosis.' Overall, this is a well-written paper on an interesting and timely topic, which could have direct implications for anti-stigma programs and for mental health clinicians. Below, I have listed the areas that need to be addressed.</p> <p>Abstract Align the study aims in the abstract (p.2) and in the introduction section (p.5, para 1) better. Insert a sub heading called 'design' and 'setting'</p> <p>Strengths and limitations of this study Statements 1-4 inclusive are not study 'strengths.' Please revise.</p> <p>Introduction. p.4, line 28: Clarify what you mean by 'more coercive care pathways' as not all readers will understand what you mean. p.5, lines 16-19. See abstract comment above.</p> <p>Methods. p.5, para 2: Provide more detail about the 'inductive' approach. p.5, line 58: Insert a separate heading called 'ethical considerations' and elaborate briefly on the main ethical issues and how these were addressed. Note. While there are similar ethical considerations for FGs and individual interviews, there are also some differences. p.6, para 2: This para. is confusing to read. Please make clearer how many focus group meeting were actually conducted and how many individual interviews (Note. There is a difference between what was 'envisaged' and what actually took place). In the event, state the average length of FGs and the individual interviews. p.7, lines 3-6: Include a table summarising the key questions that guided the FGs and interviews. p.7, para 2: Saturation: I think you are slightly misinterpreting Morse, here. I recommend you include Morse's full sentence not just the 'adequacy' bit. Morse does not disagree with the concept of saturation, or provide an alternative version; she provides helpful principles for determining saturation. p.8, para 2: Provide more detail about how data were analysed. pp.7 (line 56)-8, para 1: Insert a sub heading called 'rigour' and moved to after the 'analysis' section.</p> <p>Results Overall, this section was well-written and clear. p.9, line 57. This sentence should be moved to the end of the data</p>
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	<p>analysis section (p.8, para 2). p.15, para 1: Please shorten this overly long exemplar, but retain the essence of the key comments.</p> <p>Discussion. Overall, this was well-written and clear. p.21, lines 45-8: Insert references. I have included three recent references from a study we conducted. These may assist your discussion as some of the references were a bit dated. However, as they are from my own research it is entirely optional for you to use or ignore (I won't be offended if you decide to ignore!).</p> <p>McCann, T. V., Lubman, D., & Clark, E. (2012) Primary caregivers' satisfaction with clinicians' response to them as informal carers of young people with first-episode psychosis: a qualitative study. <i>Journal of Clinical Nursing</i>, 21, 224-231. DOI: 10.1111/j.1365-2702.2011.03836.x</p> <p>McCann, T. V., Lubman, D., & Clark, E., (2011) Responding to stigma: First-time primary caregivers of young people with first-episode psychosis. <i>Psychiatric Services</i>, 62, 548-550.</p> <p>McCann, T. V., Lubman, D., & Clark, E., (2011) First-time primary caregivers' experience of caring for young adults with first-episode psychosis. <i>Schizophrenia Bulletin</i>, 37(2), 381-388.</p> <p>p.24, line 56 to p.25, para 1: Limitations: Delete Table 2 and include information as a separate paragraph, and elaborate more so.</p> <p>Conclusions Elaborate briefly on the clinical implications of the findings.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer One

Reviewer Name Vanda Sharifi

Institution and Country: Tehran University of Medical Sciences, Tehran, Iran

Please state any competing interests or state 'None declared': None declared

This is a qualitative study to investigate different experiences of people with psychotic disorders coming from three ethnic groups. It was performed after another study in which the authors had found different DUPs across the ethnic groups. Their question is reasonable and deserves answer: Why is that and what are their experiences? However, I have major reservations about the paper.

Comment: I hope the reviewer will find this detailed list of changes and the revisions to the manuscript satisfactory.

Comment 1. The main objectives of the study seems to be comparison between the experiences across different ethnic groups. However, this is not well reflected in the title of the paper, and on the other hand, most sections of the paper is devoted to the experiences of people regardless of their ethnicity.

Answer: The title of the paper has been changed to summarize the study aims: to capture similarities and differences in pathways to care across the three ethnic groups.

As described within the paper, the study aim was to understand differences in pathways to care and DUP between African-, Caribbean-, and European-origin groups. The used of an inductive qualitative approach to examine differences in the routes to care between young people of African-, Caribbean-, and European-origin with lived experience of psychosis brought to light both similarities and differences in factors that influenced help-seeking delays across the three groups. Furthermore, as mentioned, stigma seems to play a key role in pathways to care.

Comment 2. As I understand, subjects are distributed into different focus groups but its unclear how many groups are formed and how many subjects were in each group and how many sessions were held for each group. In addition, the sample size for focus groups are very small. Only 4 caribbean patients were enrolled in the groups and no African family member. That's not enough when the authors aim to examine differences across ethnic groups.

Answer: More information about the focus groups (e.g., number of participants per groups) has been added into the manuscript.

Regarding the study sample size, qualitative studies are often based on small sample size—the emphasis is on exploring the depth of the person's experience. At the same time, we agree with the reviewer that the absence of African-background family members and the small number of Caribbean patients are a limitation of this work—see limitations.

The sample size was defined from the quantitative part of the study. As now stated within the paper: One hundred and nine people were contacted to take part in a focus group or an interview. Of these, 31 declined participation, 38 could not be reached and 40 agreed to take part in the focus group or in an individual interview. However, only 25 of these individuals could attend a focus group or an interview due to scheduling issues. NOTE: Of the 40, half of them were from European-origin group and half from African- and Caribbean-origin groups. Furthermore, all groups had more male participants than female.

Comment 3. It's not clear whether those in the groups are those with short or long DUPs especially when the authors are interested in exploring different experiences in ethnic groups.

Answer: The sample size was defined from the quantitative part of the study. As a result, we had a small group of people interested in taking part in the focus groups/interviews and we could not select/divide focus group's participants based on short or long DUP. Focus groups were implemented with a mix of people with short or long DUP; however, in an attempt to contextualize an individual's lived experience, we tried to explore key people involved in his/her journey and how long it took to receive help. Often, participants reported that it took several months, if not years, to access early intervention. They recognized changes in their behaviour, and the need for support, before the active phase of symptoms.

Comment 4. The main result of the study, according to the authors, is that internalization among the European is in the form of shame while among the minority groups is a guilt. However, the authors have not elaborated on that, nor in the results nor in the discussion section. Shame and guilt feelings are very related concepts. What are the main differentiating factor among these two feelings across the groups? Doing wrong is not the one that can best differentiate these two, at least to ordinary people. Is the guilt related to religious beliefs of people or anything to do with individualistic or collectivist attitudes? And what are the direct implications?

Answer: We agree with reviewer that feelings of shame and guilt are related concepts—often captured in existing stigma frameworks/models. In this exploratory and inductive qualitative study, the data interpretation developed from patterns found in empirical data rather than being a deductive process where a theory or hypothesis guides the data analysis and interpretation process. As mentioned within the discussion section, this work develops a preliminary hypothesis about the link between internalized stigma, cultural beliefs about mental illness, and help seeking—future studies should further explore this hypothesis and the findings. To help the reader to better understand the data analysis and interpretation more information has been added on the inductive approach to the data.

Comment 5. What about the clinical status of patients? Apparently, the subjects were in stable phase and free from psychotic symptoms. But what about being depressed? Clinical or even subclinical depression may affect reporting shame and guilt feelings to a large extent.

Answer: The reviewer is correct, study participants were in stable phase, the majority were free from active psychotic symptoms, however, some participants reported still having some psychotic symptoms but were feeling in control or able to cope with it. We cannot comment on the possibility of clinical or subclinical depression at the time of the focus groups/interviews.

Comment 6. And finally the authors have claimed that these differences show how they affect ethnic groups' differing pathways to care and delays. But they didn't explain how these feelings and attitudes can lead to delays and how the anti-stigma campaigns and equitable services can address these differences.

Answer: More information has been added to satisfy the reader.

Reviewer Two

Reviewer Name Terence McCann

Institution and Country: Victoria University, Melbourne, Australia

Please state any competing interests or state 'None declared': None declared

Thank you for giving me the opportunity to review your manuscript titled 'The African, Caribbean, & European (ACE) Pathways to Care Study: How stigma operates in defining differences in pathways to care for psychosis.' Overall, this is a well-written paper on an interesting and timely topic, which could have direct implications for anti-stigma programs and for mental health clinicians. Below, I have listed the areas that need to be addressed.

Comment 1: Abstract

Align the study aims in the abstract (p.2) and in the introduction section (p.5, para 1) better. Insert a sub heading called 'design' and 'setting'

Answer: The proposed changes have been implemented.

Comment 2: Strengths and limitations of this study

Statements 1-4 inclusive are not study 'strengths.' Please revise.

Answer: Study strengths have been revised as requested.

Comment 3: Introduction.

p.4, line 28: Clarify what you mean by 'more coercive care pathways' as not all readers will understand what you mean.

p.5, lines 16-19. See abstract comment above.

Answer: The proposed changes have been implemented.

Methods.

p.5, para 2: Provide more detail about the 'inductive' approach.

Answer: The proposed changes have been implemented. The paper provides a definition for "inductive approach" as well as how it is different from a deductive approach.

p.5, line 58: Insert a separate heading called 'ethical considerations' and elaborate briefly on the main ethical issues and how these were addressed. Note. While there are similar ethical considerations for

FGs and individual interviews, there are also some differences.

Answer: A new section on ethical considerations has been added to the paper.

p.6, para 2: This para. is confusing to read. Please make clearer how many focus group meeting were actually conducted and how many individual interviews (Note. There is a difference between what was 'envisaged' and what actually took place). In the event, state the average length of FGs and the individual interviews.

Answer: This section has been revised and focus group information has been added to the paper.

p.7, lines 3-6: Include a table summarising the key questions that guided the FGs and interviews.

Answer: A table summarizing the key questions that guided the FGs and interviews has been created and added to the manuscript—see Table 1.

p.7, para 2: Saturation: I think you are slightly misinterpreting Morse, here. I recommend you include Morse's full sentence not just the 'adequacy' bit. Morse does not disagree with the concept of saturation, or provide an alternative version; she provides helpful principles for determining saturation.

Answer: Morse's full sentence has been added to the paper.

p.8, para 2: Provide more detail about how data were analysed.

Answer: More information about data analysis has been provided. We added a section on how we used/implemented Braun and Clark's thematic analysis.

pp.7 (line 56)-8, para 1: Insert a sub heading called 'rigour' and moved to after the 'analysis' section.

Answer: A new section called 'rigour' has been created and placed after the 'analysis' section.

Results

Overall, this section was well-written and clear.

p.9, line 57. This sentence should be moved to the end of the data analysis section (p.8, para 2).

Answer: The proposed changes have been implemented.

p.15, para 1: Please shorten this overly long exemplar, but retain the essence of the key comments.

Answer: The proposed changes have been implemented. The quote has been shortened but we kept key sections/concepts.

Discussion.

Overall, this was well-written and clear.

p.21, lines 45-8: Insert references.

Answer: References have been added.

I have included three recent references from a study we conducted. These may assist your discussion as some of the references were a bit dated. However, as they are from my own research it is entirely optional for you to use or ignore (I won't be offended if you decide to ignore!).

McCann, T. V., Lubman, D., & Clark, E. (2012) Primary caregivers' satisfaction with clinicians' response to them as informal carers of young people with first-episode psychosis: a qualitative study. *Journal of Clinical Nursing*, 21, 224-231. DOI: 10.1111/j.1365-2702.2011.03836.x

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of young people with first-episode psychosis. *Psychiatric Services*, 62, 548-550.

McCann, T. V., Lubman, D., & Clark, E., (2011) First-time primary caregivers' experience of caring for young adults with first-episode psychosis. *Schizophrenia Bulletin*, 37(2), 381-388.

Answer: We thank the reviewer for the suggested references and added them to the paper and reference list.

p.24, line 56 to p.25, para 1: Limitations: Delete Table 2 and include information as a separate paragraph, and elaborate more so.

Answer: The proposed changes have been implemented.

Conclusions

Elaborate briefly on the clinical implications of the findings.

Answer: The proposed changes have been implemented in the discussion section.

VERSION 2 – REVIEW

REVIEWER	Terence McCann Victoria University, Melbourne
REVIEW RETURNED	25-Nov-2014

GENERAL COMMENTS	The authors have addressed all of my earlier comments satisfactorily. Please change year of publication of ref. 32 to 2011. Please check accuracy of all other references.
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