

## PEER REVIEW HISTORY

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## ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	The personal and social experiences of community-dwelling younger adults after stroke in Australia: a qualitative interview study
<b>AUTHORS</b>	Shipley, Jessica; Luker, Julie; Thijs, Vincent; Bernhardt, Julie

## VERSION 1 – REVIEW

<b>REVIEWER</b>	Dr Sarah Northcott City, University of London
<b>REVIEW RETURNED</b>	07-May-2018

<b>GENERAL COMMENTS</b>	<p>Thank you for the opportunity to read this paper exploring the lived experience of younger stroke survivors. The paper explores important themes such as the psycho-social impact, loss of self construct, and how concepts such as feeling invalidated by the medical system and society.</p> <p>I found the paper well written, the methodology was appropriate for the research questions, and the findings full of insight. I have some comments which may further improve the paper.</p> <p>Introduction: The authors give a neat justification of both methods chosen and rationale for study. The authors refer to quantitative literature in the specific area of young stroke – without reporting what the main findings are, nor providing any references for these studies (p3,L31). I wonder whether these quantitative findings might help to set the scene for why the current study was needed and important? A further observation is that many of the themes from the current study do mirror themes found in the general qualitative stroke literature (there is a substantial literature exploring the psychosocial reality of living with stroke). It may further strengthen this section to acknowledge some of the themes from the broader stroke literature and explore what your study may add to this. Further, some qualitative stroke literature not specifically recruiting only younger people, does explore their experiences e.g. research examining the blogs of people post stroke primarily recruited younger stroke survivors. Perhaps you could acknowledge this – and then state why there is still the need to probe in depth with your study? Or alternatively consider this in the Discussion?</p> <p>Methods Great to see that people living with stroke were involved in developing the topic guide. I found the description of your methods convincing – although perhaps be careful to explain some of your terminology that may be less familiar to readers, e.g. 'axial codes'.</p>
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	<p>Ethics – I see at the end of the manuscript that you do state that you received ethical approval. Perhaps you could also state in the main body of the text that appropriate ethical approval was received, that participants gave informed consent, and what measures you have taken to preserve anonymity of participants?</p> <p>Participants – you specify you used purposive sampling. Could you explain what criteria you used?</p> <p>Can you say whether you included people with post-stroke aphasia? If you did, can you explain what measures were taken to facilitate their responses?</p> <p>Thank you for the table listing participant characteristics. Do you have any information on severity of stroke, physical disability or presence of aphasia?</p> <p>In terms of reporting the participants who took part, this information is in the same paragraph that describes sampling procedures, recruitment methods, eligibility criteria etc. Perhaps it would help to have a separate paragraph, and also give very brief description of participant characteristics within the text – e.g. age range, time post onset, proportion employed etc. It was only in the Discussion, for example, that there is any mention that some of the participants had more severe physical disability, while some had made a near full recovery.</p> <p>Setting – from your table, I see some people took part in the interview process face to face. Consider adding this to the text (P5L46).</p> <p>Results</p> <p>I found this section well reported, with a nice use of quotes, clearly linked back to the Participant Table. It read well, the points were clearly described, and it was often moving.</p> <p>A very small point is that occasionally a particular perspective was reported twice – e.g. ‘pleasant’ (P9) P7 – giving it a sense perhaps of over prominence.</p> <p>Discussion</p> <p>As with all other sections, this was also well written and well argued. My main comment is that the authors could perhaps have referred more to other qualitative stroke literature, which mirrors so many of the findings. Having acknowledged the commonalities, I would argue it strengthens the points made about what is distinctive about having a stroke when young.</p> <p>P21L3 – typo – impairment rather than unpairment</p> <p>P21L28 – consider reframing ‘unique to stroke’? Many of the themes you list would perhaps be familiar to therapists working with e.g. young people post TBI.</p> <p>Study strengths and limitations</p> <p>I wonder if you need to acknowledge that your chosen way of conducting the interview remotely may have precluded some people from taking part? E.g. people with aphasia. I do, however, also take the point that it enabled you to include people from across Australia, which is a strength.</p> <p>I also wonder if your manner of recruitment may have meant you only recruited people able to read the flyers (or who had some family member to advocate), and who were then willing to initiate contact. It may be that some more withdrawn people, or people with language or cognitive impairment, particularly those with little family support, may not have been accessed through this route.</p> <p>In your conclusion (repeated in abstract) you make a compelling case that ‘additional support is needed’. I wonder if rather than additional, it is perhaps more the case that different support or more</p>
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	<p>bespoke support is needed to match the different needs of this younger cohort.</p> <p>In conclusion I enjoyed reading this paper. It is extremely well written, thought-provoking and beautifully draws out what is specific about having a stroke as a younger person. Well done to the authors!</p>
<b>REVIEWER</b>	<p>Bridget Davis Research Fellow, Stroke Research, Glasgow Caledonian University, UK</p>
<b>REVIEW RETURNED</b>	<p>17-May-2018</p>
<b>GENERAL COMMENTS</b>	<p>General Comments</p> <p>The subject of this paper is to examine the lived experiences of younger adults after stroke using a qualitative study design, recruiting from urban and rural area across Australia. It draws on an underpinning philosophy of social constructionism. Using thematic analysis 4 themes, each consisting of between 4 and 5 subthemes were identified.</p> <p>REVIEWER COMMENTS:</p> <p>The subject of this paper is to examine the lived experiences of younger adults after stroke using a qualitative study design, recruiting from urban and rural area across Australia. It draws on an underpinning philosophy of social constructionism. Using thematic analysis 4 themes, each consisting of between 4 and 5 subthemes were identified.</p> <p>The topic discussed is an extremely important, much overlooked area of stroke rehabilitation and it is encouraging to see that this very sensitive area has been researched. In general, the writing style is easily readable, and the paper is well written. Further comments are below.</p> <p>1. Abstract: The authors refer to 'life tasks' only within the abstract conclusion (and main text conclusion). However, the term 'life tasks' (which has a variety of definitions on quick glance elsewhere in the literature) is not defined, nor is it referred to anywhere else within the manuscript as part of any section. I would therefore question its inclusion within either of the manuscript conclusions.</p> <p>2. The results are interesting and thought-provoking. Given word count restriction they are clearly written. However, providing an 'illustrative figure' depicting themes and subthemes would give a clear representation of the analysis and be helpful to the reader to create an overall view of the results (I drew my own to help with this).</p> <p>3. In general terms descriptions about themes/subthemes that are unsupported by examples (quotes) taken directly from the data are not good practice in reporting qualitative results. This does occur within the manuscript text. Theme headlines could also better reflect their content.</p> <p>I have given a few examples of these points below:</p> <p>Theme 1.5: Poorly/briefly described in comparison to the other subthemes within Theme 1. The "direct mechanisms" at the end of the paragraph, while of potential interest, are unsupported by direct reference to data.</p> <p>Theme 2.3: Text is not well-illustrated by its headline "relations". The only relationships described with supporting quotes are 'friendships'. The sentence stating that participants had experienced breakdown of intimate/family relationships is not evidenced with quotes from the data.</p>

	<p>Theme 2.4: It is very important to include positive findings, but I wonder about having a main theme of “Losing pre-stroke life construct and relations” that includes subtheme headings relating to this (all headlined “Losing....”) and then an additional headline of “Gaining” which is an opposing view to the rest of the theme? Moreover “Gaining a new appreciation” does not signpost effectively. A new appreciation of what? Life? Relationships? This is a significant finding and deserves to be better headlined.</p> <p>Theme 4.1. Participants feeling judged by nursing staff – this is not supported by quotes from the data and is potentially contentious without evidence.</p> <p>4. Discussion: Relates well to each theme. It is not easy to incorporate so much work into one publication.</p> <p>Page 20 – The statement that “medical understanding of stroke recovery as short-term” is unsupported by the evidence. Whilst some may perceive this to be an existing attitude, long-term rehabilitation and un-met needs following stroke are being increasingly researched. It may, however, be the case that this type of research needs to be more fully extended to younger adults. Perhaps the word “understanding” may be better replaced with “rehabilitation.”</p> <p>MINOR COMMENTS:</p> <p>Suggest defining ‘short-term’ and ‘long-term’ (p8). Even a couple of words in brackets e.g. short term (≥3 months post-stroke)</p> <p>Use of speech marks within quotes to provide clarification e.g. ‘I experienced a few years of almost rage. I’d go through “Why me?” and “How come?” and all those phrases and I’d just been so angry inside myself.’ (P1) (p8)</p> <p>Data sharing statement:</p> <p>I was unable to access additional thematised participant quotations from the Dryad repository provided. The search yielded no results.</p>
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## VERSION 1 – AUTHOR RESPONSE

### REVIEWERS' COMMENTS TO AUTHOR:

Reviewer: 1

Reviewer Name: Dr Sarah Northcott

Institution and Country: City, University of London

Competing Interests: None declared

#### Reviewer comments:

Thank you for the opportunity to read this paper exploring the lived experience of younger stroke survivors. The paper explores important themes such as the psycho-social impact, loss of self construct, and how concepts such as feeling invalidated by the medical system and society.

I found the paper well written, the methodology was appropriate for the research questions, and the findings full of insight. I have some comments which may further improve the paper.

#### Introduction:

The authors give a neat justification of both methods chosen and rationale for study. The authors refer to quantitative literature in the specific area of young stroke – without reporting what the main findings are, nor providing any references for these studies (p3,L31). I wonder whether these quantitative findings might help to set the scene for why the current study was needed and important?

Thank you for this suggestion. We have strengthened our argument by adding quantitative data on return to work, institutionalisation and life satisfaction outcomes for younger stroke survivors:

*'Quantitative young stroke research has found that around half of those experiencing stroke in younger age are unable to return to full-time employment and 5% require long-term institutionalised care.<sup>4,5</sup> In a national Swedish study, more than half also reported being unsatisfied with life as a whole after young stroke.<sup>6</sup> While quantitative studies measuring functional and quality of life outcomes in large samples of younger survivors have been informative, they have offered limited insight into the lived experience of stroke in younger age...' (p3)*

**A further observation is that many of the themes from the current study do mirror themes found in the general qualitative stroke literature (there is a substantial literature exploring the psychosocial reality of living with stroke). It may further strengthen this section to acknowledge some of the themes from the broader stroke literature and explore what your study may add to this.**

Please see the next section.

**Further, some qualitative stroke literature not specifically recruiting only younger people, does explore their experiences e.g. research examining the blogs of people post stroke primarily recruited younger stroke survivors. Perhaps you could acknowledge this – and then state why there is still the need to probe in depth with your study? Or alternatively consider this in the Discussion?**

In line with these suggestions, we have now added information to the introduction on the findings of all-age qualitative stroke studies, as well as the need for research that focuses on the unique experience of younger adults:

*'While qualitative studies with participants of all ages report frustrations post-stroke such as dependence and mental health challenges,<sup>8–10</sup> there is limited primary qualitative research examining younger adults' unique experiences of stroke.<sup>11,12</sup>' (p3)*

## Methods

**Great to see that people living with stroke were involved in developing the topic guide. I found the description of your methods convincing – although perhaps be careful to explain some of your terminology that may be less familiar to readers, e.g. 'axial codes'.**

We have clarified the meaning of axial codes: *'thematic relationships between codes, or axial codes, were derived with memoing and concept mapping.'* (p6)

**Ethics – I see at the end of the manuscript that you do state that you received ethical approval. Perhaps you could also state in the main body of the text that appropriate ethical approval was received, that participants gave informed consent, and what measures you have taken to preserve anonymity of participants?**

Thank you for this comment on ethical approval. We listed this at the end of the manuscript in an attempt to reduce words, but appreciate that it is an important part of the methods and have hence re-included this in the main text. We have also moved that written informed consent was provided by participants to the ethics sub-section and added in a line about how participant anonymity was preserved.

## Ethics

*The study protocol was approved by the Austin Health Human Research Ethics Committee (HREC/16/Austin/451). Written informed consent was provided by all participants prior to participation. Anonymity was preserved by removing identifiable information from transcripts and referencing quotes by basic demographic data only.' (p4-5)*

**Participants – you specify you used purposive sampling. Could you explain what criteria you used?**

Participants were purposively sampled based on their location to ensure a national sample was recruited. No other information about participants, such as the severity of their stroke, was known at the initial point of contact. This has been clarified in the description: *'Participants were purposively sampled based on their location to ensure a national sample was recruited.'* (p5)

**Can you say whether you included people with post-stroke aphasia? If you did, can you explain what measures were taken to facilitate their responses?**

Unfortunately there were no participants with residual post-stroke aphasia. This has been added to 'Participant characteristics':

*'They reported wide-ranging stroke sequelae during the interviews (i.e., prominent physical and/or cognitive impairments to mild or no identified residual effects), though no residual post-stroke aphasia.'* (p6)

Acknowledgment of this has also been added to the limitations (see the relevant section below).

**Thank you for the table listing participant characteristics. Do you have any information on severity of stroke, physical disability or presence of aphasia?**

While clinical data on participants' stroke severity were not available to us, we have added some further description in a new paragraph on known patient characteristics (see the section below). Where possible and relevant, we have also tried to include brief descriptions of participants' stroke sequelae in the main text to provide context for particular quotes, e.g., 'one man with debilitating but invisible cognitive disability described being 'out of place' everywhere after stroke including in the 'brain injury crowd'...' (p17-18)

**In terms of reporting the participants who took part, this information is in the same paragraph that describes sampling procedures, recruitment methods, eligibility criteria etc. Perhaps it would help to have a separate paragraph, and also give very brief description of participant characteristics within the text – e.g. age range, time post onset, proportion employed etc. It was only in the Discussion, for example, that there is any mention that some of the participants had more severe physical disability, while some had made a near full recovery.**

Paragraphs have been separated into 'Participant sampling' and 'Participant characteristics'. A brief description of participant characteristics was also added to the latter.

*'Participant characteristics*

*There were 19 participants in total (see participant and interview characteristics in Table 1). Participants were aged 19 to 54 at diagnosis and ranged from 6 months to 24 years post-stroke. They reported wide-ranging stroke sequelae during the interviews (i.e., prominent physical and/or cognitive impairments to mild or no identified residual effects), though no residual post-stroke aphasia. Support persons were also present in three interviews at the request of participants, but their contributions were not included for analysis.'* (p5-6)

The description of stroke effects in parentheses was initially included in the discussion. This has been removed from the discussion section to reduce repetition and excess words.

**Setting – from your table, I see some people took part in the interview process face to face. Consider adding this to the text (P5L46).**



'Face-to-face' is now included in the 'Setting' sub-section of the methods: *'Interviews took place face-to-face in a private setting in a clinic room of the Florey (Melbourne, Australia), over an online conference platform, or by telephone.'* (p6)

## Results

**I found this section well reported, with a nice use of quotes, clearly linked back to the Participant Table. It read well, the points were clearly described, and it was often moving. A very small point is that occasionally a particular perspective was reported twice – e.g. 'pleasant' (P9) P7 – giving it a sense perhaps of over prominence.**

We agree with the suggestion to avoid duplicating this quote. As such, the first quoted use of 'pleasant' has been replaced by 'positive': *'Psycho-emotional experiences of the acute stroke event also varied among participants, ranging from traumatic to even positive.'* (p7)

## Discussion

**As with all other sections, this was also well written and well argued. My main comment is that the authors could perhaps have referred more to other qualitative stroke literature, which mirrors so many of the findings. Having acknowledged the commonalities, I would argue it strengthens the points made about what is distinctive about having a stroke when young.**

Thank you for this suggestion. We agree and have added a new paragraph to the discussion to address this:

*'While younger adults experience many of the same functional and psychosocial consequences of stroke as older people, some important effects appear to be age-specific. For example, all-age studies report challenges to mental wellbeing and social participation after stroke.<sup>10,11</sup> However, consequences of stroke that are either unique or heightened in younger populations include difficulties fulfilling roles specific to young age and feeling invalidated by the old-age concept of stroke.'* (p21)

## P21L3 – typo – impairment rather than unpairment

Thank you for identifying this typo. It has now been corrected: *'discrediting of their own invisible impairments as potentially fabricated or exaggerated.'* (p21)

## P21L28 – consider reframing 'unique to stroke'? Many of the themes you list would perhaps be familiar to therapists working with e.g. young people post TBI.

We agree that many of these themes are also relevant to younger people who have experienced a TBI. We have added an additional acknowledgement of this while also trying to draw out what is specific to young stroke, which is especially relevant to the final two points in the list. This section now reads:

*'However, unique to brain injury, and specifically stroke in young age, is the acquisition of physical, cognitive and/or affective impairment, the need to define oneself within the confines of disability language, the invalidation from the social construct of stroke, and the continued lack of awareness of the occurrence in younger age.'* (p22)

## Study strengths and limitations

**I wonder if you need to acknowledge that your chosen way of conducting the interview remotely may have precluded some people from taking part? E.g. people with aphasia. I do, however, also take the point that it enabled you to include people from across Australia, which is a strength.**

As you have mentioned, we provided the option of conducting interviews online or by telephone to include participants across Australia, including those living in more remote settings. It's very unfortunate that we did not have any participants with residual post-stroke aphasia, which may have been a result of our recruitment method or the way the interviews were conducted. Future studies could adopt methods to better include participants with post-stroke aphasia, e.g., explicitly stating that

those with aphasia are invited to participate and adopting supportive communication strategies in the interviewing process. We have added an acknowledgement of this in the limitations sections:

*'The authors also acknowledge that there were no participants with residual post-stroke aphasia, which may be a result of the recruitment or interviewing methods. Future studies could adopt strategies to better include participants with language impairment, e.g., explicitly inviting those with language difficulties in the recruitment material and using supportive communication strategies in the interviewing process.'* (p22)

**I also wonder if your manner of recruitment may have meant you only recruited people able to read the flyers (or who had some family member to advocate), and who were then willing to initiate contact. It may be that some more withdrawn people, or people with language or cognitive impairment, particularly those with little family support, may not have been accessed through this route.**

In addition to acknowledging the means of conducting the interview as potentially excluding participants with language impairment, we have acknowledged the method of recruitment as potentially contributing to this (see above).

We agree that some more withdrawn people may not have been accessed by our recruitment route, but we were reassured that we did reach some socially isolated individuals who gave insightful descriptions of their experiences, e.g., 'when I had the stroke and came home... nobody came... I was that desperate to talk to people, and I know it sounds awful this, but I got a knock on the door by Jehovah's witnesses and I invited them in for a cup of tea and a chat because they were the only people that came'.<sup>(P2)</sup> We believe that the limitations now acknowledge the main points of this reviewer and we have not amended further.

**In your conclusion (repeated in abstract) you make a compelling case that 'additional support is needed'. I wonder if rather than additional, it is perhaps more the case that different support or more bespoke support is needed to match the different needs of this younger cohort.**

Thank you for this suggested edit, which has made our conclusion about the need for services specific to younger stroke services clearer. As such, we have replaced 'additional support' with 'more bespoke support' as follows: '*... this study suggests that more bespoke support is needed for younger adults after stroke.*' (p2,23)

**In conclusion I enjoyed reading this paper. It is extremely well written, thought-provoking and beautifully draws out what is specific about having a stroke as a younger person. Well done to the authors!**

**Reviewer: 2**

**Reviewer Name: Bridget Davis**

**Institution and Country: Research Fellow, Stroke Research, Glasgow Caledonian University, UK**

**Competing Interests: None declared**

**Reviewer comments:**

**The subject of this paper is to examine the lived experiences of younger adults after stroke using a qualitative study design, recruiting from urban and rural area across Australia. It draws on an underpinning philosophy of social constructionism. Using thematic analysis 4 themes, each consisting of between 4 and 5 subthemes were identified.**

**The topic discussed is an extremely important, much overlooked area of stroke rehabilitation and it is encouraging to see that this very sensitive area has been researched. In general, the writing style is easily readable, and the paper is well written. Further comments are below.**



**1. Abstract:** The authors refer to 'life tasks' only within the abstract conclusion (and main text conclusion). However, the term 'life tasks' (which has a variety of definitions on quick glance elsewhere in the literature) is not defined, nor is it referred to anywhere else within the manuscript as part of any section. I would therefore question its inclusion within either of the manuscript conclusions.

We have changed the term 'life tasks' to 'roles' in both the abstract and manuscript conclusions: *'For many younger adults, stroke is an unexpected and devastating life event that profoundly diverts their biography and presents complex and continued challenges to fulfilling age-normative roles.'* (p2,23)

**2. The results are interesting and thought-provoking. Given word count restriction they are clearly written. However, providing an 'illustrative figure' depicting themes and subthemes would give a clear representation of the analysis and be helpful to the reader to create an overall view of the results (I drew my own to help with this).**

Thank you for this advice. The following illustrative figure has been added with the link at the beginning of the results: *'Four main themes and several sub-themes emerged from the discourses (see the thematic model in Figure 1).'* (p7)

The high-definition form is present in the proof (p29).

*Figure 1. Thematic model*

**3. In general terms descriptions about themes/subthemes that are unsupported by examples (quotes) taken directly from the data are not good practice in reporting qualitative results. This does occur within the manuscript text. Theme headlines could also better reflect their content. I have given a few examples of these points below.**

We agree that it is not good qualitative research practice to include points without a supporting quote. As such, we have embedded some additional quotes in the results. In order to keep the paper to a reasonable word count, further evidence is included in the 'additional thematised quotations' document in the Dryad repository. We are sorry to hear that you did not have access to this at the time of reviewing this manuscript. We provided it in the Dryad repository and have now uploaded it as a supplementary file for Editors only (Supplement 2). As per your comment, we have also tried to improve the headlines, as detailed below.

**Theme 1.5: Poorly/briefly described in comparison to the other subthemes within Theme 1. The "direct mechanisms" at the end of the paragraph, while of potential interest, are unsupported by direct reference to data.**

Thank you for this remark. Further evidence has been added to support the coping mechanisms described in this sub-theme.

*'For many participants, it took years to come to terms with the stroke diagnosis. Time itself was identified as one important mitigating factor to 'detrimental' thinking. (P4) One participant described, 'I think about it every day obviously, but I'm not thinking about it as detrimentally as before. It's more in the past now'. (P4) Participants also described using different mechanisms to cope with what had happened, including focusing on the way forward, occupying the mind and setting goals. One participant described, 'I had this idea that if I stopped depression would just consume me... so I had this idea that I... would have my runners on and just work and... socialise and see how far I get'. (P12) Humour was also used as a coping mechanism 'because if you don't laugh about it, you just cry'. (P17)' (p10)*

**Theme 2.3: Text is not well-illustrated by its headline "relations". The only relationships described with supporting quotes are 'friendships'. The sentence stating that participants had experienced breakdown of intimate/family relationships is not evidenced with quotes from the data.**

We originally chose to use the word 'relations' to incorporate both relation to oneself and relationships in general, but 'relationships' is a clearer term for the headline. We have changed the name of the theme accordingly: '*Losing pre-stroke life construct and relationships*' (p10)

Loss of friendships has been described in most depth because this came through as a very prominent and common theme in the interviews, but loss of and strain in intimate and family relationships was also apparent. We have added a supportive quote for this:

*'Adding to these losses, many participants recounted breakdown of relationships and social isolation after stroke. The most prominent contributor to this was loss of friendships. Participants reasoned that their friends didn't know how to approach the situation, visiting required too much effort, they were no longer able to connect over shared social activities such as running, and there was loss of the balance needed to maintain a reciprocal friendship. Some participants also experienced breakdown of intimate and family relationships with one participant describing 'I lost my wife and my home life... and that was taken away from me because she couldn't live that way anymore'.<sup>(P2)</sup> Loss of relationships had a significant impact on the lives of many participants...' (p12)*

**Theme 2.4: It is very important to include positive findings, but I wonder about having a main theme of "Losing pre-stroke life construct and relations" that includes subtheme headings relating to this (all headlined "Losing....") and then an additional headline of "Gaining" which is an opposing view to the rest of the theme? Moreover "Gaining a new appreciation" does not signpost effectively. A new appreciation of what? Life? Relationships? This is a significant finding and deserves to be better headlined.**

Thank you for pointing out that the headline could be more effectively named. We have changed it to '*Gaining a new appreciation for the important things in life*' (p13). Loss was a very prominent theme in the interviews, but participants also made the point that through all of the loss they also experienced some important gains.

**Theme 4.1. Participants feeling judged by nursing staff – this is not supported by quotes from the data and is potentially contentious without evidence.**

This line has been removed and the emphasis shifted to dismissive treatment experienced within the medical structure in general. Evidence for this is provided in the Dryad repository (4.1.1. and 4.1.2.). The section now reads as follows: '*Upon initial presentation to the emergency department, many participants described that their condition was dismissed as drug or alcohol-related. Some also related that stroke was explicitly dismissed as a diagnosis because of their younger age.*' (p16)

**4. Discussion: Relates well to each theme. It is not easy to incorporate so much work into one publication.**

**Page 20 – The statement that "medical understanding of stroke recovery as short-term" is unsupported by the evidence. Whilst some may perceive this to be an existing attitude, long-term rehabilitation and un-met needs following stroke are being increasingly researched. It may, however, be the case that this type of research needs to be more fully extended to younger adults. Perhaps the word "understanding" may be better replaced with "rehabilitation."**

We have re-worded this section to focus on the rehabilitation model, as follows: '*This differs from the short-term model of post-stroke rehabilitation grounded in the concept of stroke recovery as short-term with definitive plateauing and suggests that recovery may be augmented by longer-term rehabilitation and clinical support than is presently offered.*' (p20)

#### **MINOR COMMENTS:**

**Suggest defining 'short-term' and 'long-term' (p8). Even a couple of words in brackets e.g. short term (≥3 months post-stroke).**

We have now defined short-term: 'short-term and reactive (grief, <6 months)' (p9)

**Use of speech marks within quotes to provide clarification e.g. 'I experienced a few years of almost rage. I'd go through "Why me?" and "How come?" and all those phrases and I'd just been so angry inside myself.' (P1) (p8)**

Thank you for this comment. Adding in speech marks has made the quotes clearer. They have been added in all of the following instances:

'... thinking "I'm dying"'<sup>(P2)</sup> (p7); "why me" and "why God"<sup>(P1,P2)</sup> (p8); '... I'd go through "why me?" and "how come" and all those phrases...' <sup>(P1)</sup> (p8); '... it's like "why can't you do it?"'<sup>(P10)</sup> (p11); 'I'll say you know to family... "oh I'm disabled" and someone will say "you're not disabled"... "but I am I suppose"...' <sup>(P19)</sup> (p12); "oh can I open the door for you"... it just... reminds you that you're different<sup>(P8)</sup> (p15); '[exclaiming] "you're just too young, that's stupid, that's ridiculous"'<sup>(P8)</sup> (p16-17); 'they sort of look at you like "oh were you on drugs... or are you a smoker?"'<sup>(P17)</sup> (p17); "lucky" or "fine"<sup>(P3,P13)</sup> (p17); 'it actually hurts when people say "you got out of it okay"...' <sup>(P5)</sup> (p17); 'a stroke survivor doesn't say "gee you look great, I can't even tell you've had a stroke", which is what everyone else says'<sup>(P7)</sup> (p17); 'some of them go, "why are you here mate?"'<sup>(P9)</sup> (p18)

# **Data sharing statement:**

**I was unable to access additional thematised participant quotations from the Dryad repository provided. The search yielded no results.**

As above, we apologise that you were not able to access the additional thematised quotations. The Dryad repository DOI will be searchable when the article is published. The thematised quotations are now available for viewing as supplementary material for Editors only (Supplement 2).

## **VERSION 2 – REVIEW**

<b>REVIEWER</b>	Dr Sarah Northcott City, University of London, UK
<b>REVIEW RETURNED</b>	27-Jul-2018

<b>GENERAL COMMENTS</b>	Thank you for the opportunity to read this revised version of the manuscript. The authors have responded thoughtfully and appropriately to the reviewer suggestions. The paper reads well, and is stronger as a result of the various revisions made. It addresses an important topic in a thoughtful manner: it has been a pleasure to read this paper.
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<b>REVIEWER</b>	Bridget Davis Glasgow Caledonian University, UK
<b>REVIEW RETURNED</b>	31-Jul-2018

<b>GENERAL COMMENTS</b>	This manuscript clearly presents the lived experiences of younger adults after stroke using a qualitative study design, recruiting from urban and rural area across Australia. Many thanks to the authors for their considered and thorough response to reviewer comments. As I have previously stated, this is a well written, interesting and often moving manuscript relating to a much-deserved topic. Your work is well researched, and I think the inclusion of your thematic model strengthens the analysis; it is clear, concise and easy to read. Well done, I look forward to reading the final publication.
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