

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Longer-term needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies.
AUTHORS	Wray, Faye; Clarke, David

VERSION 1 - REVIEW

REVIEWER	Miranda L. Rose La Trobe University, Australia
REVIEW RETURNED	18-Jun-2017

GENERAL COMMENTS	<p>The current qualitative thematic synthesis is well motivated and carried out with high attention to methodological rigor including adequate credibility, transferability, dependability and confirmability. The manuscript is very well written.</p> <p>I have two suggestions for revision:</p> <p>Missing reference Introduction, p.5 The authors state that there has been no systematic synthesis of stroke survivor's perspectives of living with a communication disability., and use such a lack as their rationale for the current review. There is an existing synthesis review of qualitative studies of people with aphasia experiencing support from community and peer support groups that I believe should be addressed in the introduction. Attard, M., Lanyon, M., Togher, L., & Rose, M. (2015). Consumer perspectives on community aphasia groups. A narrative literature review in the context of psychological wellbeing. <i>Aphasiology</i>, 29(8), 893-1019.</p> <p>Novelty of findings The major concern I have with this work is that the findings do not seem sufficiently different from the individual studies they synthesise and thus I am unconvinced of the overall novelty of the findings here beyond the amount or weight of them provided through synthesis. For example, the 4 main themes from this thematic synthesis: 1) Coming to terms with loss of communication; 2) Loss of communication and loss of self identity; 3) Isolation and exclusion from social situations; and 4) A support network of family and friends; can all be extracted from Grohn et al (2014) <i>Aphasiology</i>. If this is the case then the authors should acknowledge that the themes are similar to many of articles they drew the data from and emphasise the weight of the evidence emerging from this current</p>
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	synthesis. At the very least I would expect the discussion to highlight where the “new” themes were similar or different to previously published themes.
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REVIEWER	Linda Worrall The University of Queensland, Australia.
REVIEW RETURNED	19-Jun-2017

GENERAL COMMENTS	<p>This was an extremely enjoyable read. It was a thorough and comprehensive thematic synthesis of 32 qualitative studies that had been found through a systematic review. I particularly liked the two stages of analysis of descriptive and interpretive levels so that future interventions could be developed. The clarity of writing and the explanations of methodology were superb. The findings are also highly significant and point to ways of improving the long term outcomes of people with aphasia.</p> <p>The last search was conducted in 2015. This may be considered a drawback but it often happens when a PhD commences with a systematic review. An updated search may find additional publications but it is unlikely that any additional publications will change the final themes. The authors may wish to rerun the search terms just to check and provide a table with the findings of any additional publications in a table in the response to reviewer’s comments.</p> <p>A potential limitation of this review is that it has been limited to qualitative research. What might have quantitative research added? This could be commented on in the Discussion.</p> <p>I look forward to reading the next set of publications from this team about the development of self-management interventions. The team may also wish to consider how non-self-management programs may need to include additional interventions to address these long term outcomes for people with aphasia. This discussion may be included in the next publication.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1: Miranda L. Rose

Reviewer comment: Missing reference

Introduction, p.5 The authors state that there has been no systematic synthesis of stroke survivor’s perspectives of living with a communication disability, and use such a lack as their rationale for the current review. There is an existing synthesis review of qualitative studies of people with aphasia experiencing support from community and peer support groups that I believe should be addressed in the introduction.

Attard, M., Lanyon, M., Togher, L., & Rose, M. (2015). Consumer perspectives on community aphasia groups. A narrative literature review in the context of psychological wellbeing. *Aphasiology*, 29(8), 893-1019.

• Author’s revision/comments:

We were unaware of this existing literature review which was published after the initial searches for our review had been conducted. We did search for similar reviews before submitting the manuscript but unfortunately we did not identify this reference. We have now acknowledged this review in the introduction and have updated our rationale (p.5) and the strengths and limitations of the study (p.3) in light of this. We believe the rationale for our review is still strong given the different focus of the two

reviews (ours upon longer-term needs and Attard et al.'s upon participant's experiences of community aphasia groups). Due to the different focus of the two reviews there is no overlap with the 11 primary studies identified by Attard et al.'s (2015) review and the studies identified and synthesised in our own review. Our review is more broadly focused upon the day to day experiences of stroke survivors with communication difficulties and the implications of this upon longer-term needs. Studies exploring experience in relation to a specific intervention (e.g. community aphasia groups) were excluded from our review.

Reviewer comment: Novelty of findings

The major concern I have with this work is that the findings do not seem sufficiently different from the individual studies they synthesise and thus I am unconvinced of the overall novelty of the findings here beyond the amount or weight of them provided through synthesis. For example, the 4 main themes from this thematic synthesis: 1) Coming to terms with loss of communication; 2) Loss of communication and loss of self identity; 3) Isolation and exclusion from social situations; and 4) A support network of family and friends; can all be extracted from Grohn et al (2014) Aphasiology. If this is the case then the authors should acknowledge that the themes are similar to many of articles they drew the data from and emphasise the weight of the evidence emerging from this current synthesis. At the very least I would expect the discussion to highlight where the "new" themes were similar or different to previously published themes.

• Author's revision/comments:

We acknowledge your concerns regarding the novelty of the findings and recognise the similarity between the findings of the individual studies and the four analytical themes developed in the thematic synthesis. We believe that a strength of the review is that the product of the synthesis reflects the existing findings in this area such as those reported by Grohn et al. (2014) and other papers included in the thematic synthesis. In the manuscript we demonstrate how we used a systematic method to summarise and interpret the existing literature in order to address a specific research question. Although the themes stay close to the findings of the individual studies, by drawing the findings of these studies together we have created an overall interpretation of the literature in relation to longer-term need.

The analytical themes go beyond a descriptive summary of study findings by identifying the implications of the findings for understanding the longer-term needs of stroke survivors with communication difficulties and by using this information to make reasoned recommendations for future intervention development. Rather than claiming the novelty of the themes per se, we believe the synthesis allows us to demonstrate the weight of the evidence, to clearly articulate the types of difficulties experienced by this group of stroke survivors and the implications of this for future intervention development. Drawing this information together has allowed us to conclude with confidence that there is significant need for a distinctive form of longer-term support for stroke survivors with communication difficulties. We have clarified this point in the discussion (p.29/31).

Reviewer 2: Linda Worrall

Reviewer comment: The last search was conducted in 2015. This may be considered a drawback but it often happens when a PhD commences with a systematic review. An updated search may find additional publications but it is unlikely that any additional publications will change the final themes. The authors may wish to rerun the search terms just to check and provide a table with the findings of any additional publications in a table in the response to reviewer's comments.

• Author's revision/comments:

Thank-you for understanding the difficulties of maintaining a systematic review within the context of a busy PhD. We re-ran the searches for the databases of published literature on the 26th June 2017 and identified 3 additional studies in the search from 2015 to 2017. As suggested the references are listed below and a summary of the main findings follows each citation.

1. Armstrong E, Hersh D, Hayward C, et al. Communication disorders after stroke in aboriginal Australians. *Disability and Rehabilitation* 2015;37(16):1462-69.

Findings: Semi-structured interviews were undertaken with 13 aboriginal people with post-stroke communication disorders (aphasia or dysarthria). Participant's time post-stroke ranged from 0.5 to 29 years. The findings included six themes; getting on with life, coping with change, independence/interdependence, the importance of communication for maintaining family and community connection, role and identity issues, and viewing the stroke within the broader context of comorbidities.

2. Horn DEA, Crews JA, Guryan BA, et al. Identifying and addressing grief and loss issues in a person with aphasia: A single-case study. *Journal of Counseling & Development* 2016;94(2):225-33.

Findings: Horn et al. (2016) present the analysis of a set of interviews with a single participant "Lynn" who is living with aphasia and is approximately 2 years post-stroke. Five themes were identified from the interviews which included; questioning identity, questioning existence, questioning normality, questioning feelings and adapting to a new reality.

3. Mc Menamin R, Tierney E, Mac Farlane A. Addressing the long-term impacts of aphasia: How far does the Conversation Partner Programme go? *Aphasiology* 2015;29(8):889-913.

Findings: McMenamin et al. (2015) explored five participant's experiences of aphasia using a group-based card sort technique. Participant's time post-stroke ranged from 3 to 10 years. Eight themes were developed which included; back to pre-school, tiredness, it's like a prison, emotions, not able to talk the words, escape, changing and adapting and family.

Having reviewed the findings of the additional publications we believe they are highly consistent with the themes developed in our own synthesis. The publications highlight the significant and continuing need for longer-term support experienced by stroke survivors with communication difficulties. We acknowledge that two of the themes identified in the publications are captured less clearly within our synthesis; 'viewing the stroke within the broader context of comorbidities' (Armstrong et al., 2015) and 'tiredness' (McMenamin et al., 2015).

The first theme identified by Armstrong et al. (2015) acknowledges that some participants in their study had significant comorbidities, for example, diabetes and heart disease and that these difficulties were perceived to be of greater importance by participants than the ongoing difficulties as a result of stroke (e.g. aphasia). The second theme of 'tiredness' identified by McMenamin et al. (2015) describes how fatigue impacted some participant's ability to communicate and how the effort of communication was perceived to lead to increased levels of fatigue. We acknowledge the minor differences in the findings of these studies and our own synthesis, however, we do not believe that the inclusion of these publications would have impacted upon the final themes or conclusions of our synthesis and therefore the manuscript has not been revised to include these publications.

Reviewer comment: A potential limitation of this review is that it has been limited to qualitative research. What might have quantitative research added? This could be commented on in the Discussion.

• Author's revision/comments: We believe quantitative research in this area is very limited at this point in time, particularly with regards to the robust evaluation of longer-term care interventions through randomised controlled trials. However, there is a growing interest in this field, for example in the development and evaluation of psychosocial interventions for stroke survivors with communication difficulties. We have commented upon this in the discussion and cited some of the emerging research in this field (p.31).

Reviewer comment: I look forward to reading the next set of publications from this team about the development of self-management interventions. The team may also wish to consider how non-self-management programs may need to include additional interventions to address these long term outcomes for people with aphasia. This discussion may be included in the next publication.

• Author's revision/comments: Thank-you for your comments which we hope we will be able to discuss in more detail in a future publication. In a future paper we plan to draw together the findings from the current review and from our previous review of self-management interventions (Wray, Clarke and Forster, 2017) in a 'meta-synthesis'. The meta-synthesis will consider whether self-management interventions meet the needs of stroke survivors with communication difficulties in relation to longer-term care. In this publication we hope to discuss additional, non-self-management interventions, which might be needed to support stroke survivors with communication difficulties in the longer-term.

VERSION 2 – REVIEW

REVIEWER	Miranda L. Rose La Trobe University
REVIEW RETURNED	28-Jul-2017

GENERAL COMMENTS	The authors have addressed the review concerns through their text additions. I am satisfied this work makes a substantial contribution to the literature and look forward to its utility in the field.
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