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Title page

A meta-synthesis of qualitative research on perceptions of people with long-term neurological conditions about group-based memory rehabilitation

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Abstract

The effectiveness of memory rehabilitation based on randomised controlled trials and meta-analyses has been inconclusive, but patient reports based on qualitative studies have been largely positive. We conducted a meta-synthesis of qualitative studies of group-based memory rehabilitation programmes for people with neurological conditions. Based on systematic searches of electronic databases and reference lists, five papers (87 participants) were selected. Quality appraisal of papers was conducted by two independent reviewers using the Critical Appraisal Skills Programme tool. Data synthesis was guided by the meta-ethnography approach. Five higher order themes were elicited. These suggested that memory rehabilitation was associated with *insight and acceptance* of participants' neurological condition and resultant cognitive deficits. The *therapeutic effects of the groups*, with social support and leisure activities, helped with participants' confidence. There were *improvements in memory* related to better self-awareness and learning to use new skills and strategies to compensate for memory deficits. These improvements also related to *other psychological effects*, in terms of positively affected mood, confidence and fatigue. Ultimately, these changes had a positive *impact on daily life*, with changes seen in the personal, inter-personal and professional spheres. Therefore, this synthesis of qualitative studies suggests that memory rehabilitation offers positive outcomes for people with long-term neurological conditions.

Key words: Neurological conditions, memory, cognitive rehabilitation, qualitative analysis, meta-synthesis.

Main Text

Introduction

Neurological conditions are caused by damage to the brain or nervous system, the aetiologies of which fit broadly into the following four groups: sudden-onset (such as stroke, or traumatic brain injury); intermittent and unpredictable (such as epilepsy); progressive (dementia, Parkinson's

disease); and stable (e.g. cerebral palsy in adults) (National Audit Office, 2011). There are currently 10 million individuals in the UK living with a neurological condition (The Neurological Alliance, 2003). Cognitive deficits are common sequelae of these conditions and memory problems appear to be very common (Radford, Lah, Thayer, Say, & Miller, 2012). Between 40-60% of individuals with multiple sclerosis (MS) (Rao et al., 1993) and traumatic brain injury (TBI) (Goldstein & Levin, 2001) experience memory problems. In addition, memory impairments are one of the most commonly reported cognitive impairments in stroke survivors (Tatemichi et al., 1994), and in individuals who survive encephalitis, 70% of whom report problems with memory (Wilson, 2002).

Memory deficits can disrupt not only the personal lives of people with neurological conditions, but also their social, professional and family lives (Ownsworth & McFarland, 1999). They may also affect the extent to which patients engage with other medical interventions and rehabilitation (Mitchell & Selmes, 2007). The safety of such patients can be compromised, making them vulnerable citizens in the home (e.g., forgetting to turn the stove off), community (e.g., forgetting road rules), and work (e.g., forgetting important documents) settings.

Cognitive rehabilitation is a neuropsychological approach involving a structured set of therapeutic activities aimed at improving overall cognitive function through the retaining of previously learned skills and the acquisition of strategies designed to compensate for lost abilities (Tsaousides & Gordon, 2009). There are recommendations for the provision of cognitive rehabilitation for people with neurological conditions (Cappa et al., 2005; National Audit Office, 2005), however implementation of these guidelines have been poor and specialist neuro-rehabilitation continues to be underprovided (National Audit Office, 2011; Neurological Commissioning Support, 2010). Potential reasons for this include a lack of research that unequivocally demonstrates the clinical and cost-effectiveness of cognitive rehabilitation.

Memory rehabilitation is a subset of cognitive rehabilitation, delivered to patients with memory problems. The majority of evidence regarding the effectiveness of memory rehabilitation in people with neurological conditions comes from single case experimental design studies, non-randomised controlled trials (RCTs), and small pilot RCTs. Nevertheless, there have been some RCTs indicating memory rehabilitation is effective in people with a range of neurological conditions (Hildebrandt et al., 2007; Solari et al., 2004; Stuifbergen et al., 2012; Westerberg et al., 2007). However, systematic reviews of memory rehabilitation have found no evidence to support or refute the effectiveness of such programmes (Brissart et al., 2011; das Nair, Ferguson, Stark, & Lincoln, 2012; das Nair & Lincoln, 2007; O'Brien, Chiaravalloti, Goverover, & Deluca, 2008; Rohling, Faust, Beverly, & Demakis, 2009). This lack of evidence is partly due to the paucity of well-designed trials, and has led a recent meta-analysis to conclude that “the results for memory rehabilitation are mixed and weak” (Rohling et al., 2009, page 33). While methodological limitations of RCTs may be one reason for the lack of evidence, other reasons could be that the measures used to assess clinically significant changes are not robust enough to pick up the small, but personally significant changes that people may experience as a result of memory rehabilitation (das Nair & Lincoln, 2013). Therefore, to suggest that memory rehabilitation is not effective for people with neurological conditions is perhaps premature, particularly in light of the patient-reported benefits seen in qualitative studies of memory rehabilitation.

Qualitative studies offer us the opportunity to determine patients' views on how they experienced the intervention, what (if any) changes they observed as a result of the intervention, and their perspective on the mechanism of such change. These are often not examined by quantitative outcome measures, particularly in RCTs, where outcomes are kept to a minimum. Therefore, focus on patient perspectives are vital here. There is no doubt that reporting biases may affect the findings of qualitative studies, but this criticism could also be levelled against most quantitative patient-reported outcome measures (PROMs), in the absence of control groups, as both offer subjective patient perspectives.. Another criticism of qualitative studies relates to the generalizability of their

findings, owing to the purposive sampling strategies used and the small participant numbers involved. Qualitative researchers, however, argue that what is lost in terms of sample size is gained in terms of attending to the context, and the detail and depth of the data analysis. Some of these criticisms have been dealt with elsewhere (see Mays & Pope 1995). In fact, the value of qualitative studies has been increasingly recognised in contributing to our understanding of traditional RCTs that there are now standard operating procedures for clinical trials units that intend to use such a design (e.g. Rapport et al. 2013). Meta-synthesis attempts to integrate data from different qualitative studies that are related in topic area or focus, and can deepen understanding of the contextual dimensions of healthcare (Walsh & Downe, 2005).

Aims

This review aimed to synthesise findings from qualitative studies of patients with neurological conditions who had received group-based memory rehabilitation, to gain an in-depth understanding of their experiences of the interventions. We only studied group-based programmes because the group provides an extra dynamic that could influence the perceived outcomes of the intervention, and also to increase the homogeneity of the interventions to allow for comparisons between studies.

Methods

This meta-synthesis took a critical realist epistemological position. Such a position does not question the *truth* of the data (a realist ontology), but acknowledges the constructive aspects of the narratives that *form* the data (an interpretive epistemology) (Bhaskar, 2013). We viewed the data from this position and not others (such as social constructionist, Freudian, etc.) because we were keen to view the data not from any one specific vantage point. We have, therefore, chosen to use Noblit and Hare's meta-ethnography approach (Noblit & Hare, 1988), which is described in detail later. The meta-synthesis was conducted in four stages, outlined below.

Stage 1: Systematic literature search

A search strategy was developed based on the following inclusion/exclusion criteria, which were defined:

We included studies that had adult patients with any neurological condition (of single or multiple aetiologies) who had memory rehabilitation (or cognitive rehabilitation with a specific focus on memory) delivered in a group format (defined as more than two participants). The group intervention had to be with patients (although studies that included both patients and carers were considered, but the paper needed to clearly identify whether the data were from patients or carers) and the papers needed to report direct quotes based on patient interviews or focus groups. We considered mixed-methods studies, as long as there were distinct 'qualitative' data.

The following hierarchy of exclusion was used when searching the studies:

1. Non-empirical articles
2. Not a qualitative methodology
3. Not a neurological disorder
4. Not adults
5. Not focussed on memory
6. Non-intervention papers
7. Not a group intervention
8. Intervention not patient-focussed (i.e., it was for carers or staff)
9. No interview/focus group data

The quality of the study was not considered at this stage, as all relevant studies, irrespective of their quality, potentially had important data to contribute to this review. Furthermore, as Dixon-Woods, Booth and Sutton (2007) suggested, suggested, it is not appropriate for qualitative reviews to use

quality indicators as a decision-making tool for inclusion or exclusion. This said, we did not include studies that did not meet some of the *basic requirements* of a qualitative study (e.g., an indication of the sampling methods, direct quotes from participants, etc.) as this would limit the possibility of obtaining the relevant data, and deriving robust and nuanced interpretations from such studies.

A systematic search was conducted on the following electronic bibliographic databases from their inception until September 2013: Web of Knowledge, Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE, Allied and Complimentary Medicine Database (AMED), EMBASE and PsychInfo. A search strategy was created for MEDLINE and amended for each database (see Appendix A for details). Alerts were set up to highlight new relevant studies published between the initial searches until the time of analysis. The search was repeated in January 2014 to ensure there had not been any relevant articles subsequently published. Reference lists of included papers were searched to identify further potential studies. Each citation was checked for relevance by two researchers (KM & ES) independently using the title and when relevance was in doubt the abstract was obtained. In cases where the abstract provided insufficient detail, full papers were accessed. If there was disagreement regarding inclusion or exclusion of a paper, a third researcher (RdN) arbitrated. Only English language papers were included. See figure 1 for the flow diagram.

Figure 1 here

Stage 2: Data extraction

Data extraction forms were developed, and two researchers (KM & ES) extracted the data. These data are presented in table 1. We preserved the *tone* and *feel* of the included studies by reproducing the language used in the original text (Walsh & Downe, 2005). This was done to address the postmodernist critique that synthesising qualitative studies is reductionist exercise.

Table 1

Stage 3: Quality appraisal of included studies

The quality of the studies was assessed to avoid over- or under-reliance of certain findings, which could affect the interpretations of the findings from primary studies (Dixon-Woods, Booth, & Sutton, 2007). In line with a previous meta-syntheses (Wilkinson & das Nair, 2013), we used the Critical Appraisal Skills Programme tool (CASP, 2010) to assess the quality of included studies. The CASP can be used to assess studies employing various qualitative methods. It comprises questions that deal with some of the assumptions and principles that characterise qualitative research.

Stage 4: Data synthesis

There has been no consensus amongst qualitative researchers as to how best to synthesise qualitative data (Dixon-Woods et al. 2007; Noyes, Popay, Pearson, Hannes & Booth, 2008; Thorne, Jensen, Kearney, Noblit & Sandelowski 2004), and various strategies have been suggested (e.g., meta-ethnography by Noblit & Hare, 1998; case-study meta-synthesis by Hoon, 2013). Our data synthesis was guided by the meta-ethnography approach (Noblit & Hare, 1988). This was achieved by reading and re-reading the original papers, noting down the themes and subthemes presented in each paper along with the original data extracts (quotes), determining how these themes and subthemes were related, separating out independent themes and combining common themes ('reciprocal synthesis' records similarities of content and themes across studies) and looking for negative or 'deviant' case examples throughout ('refutational synthesis' addresses conflicting content or themes across papers and offers competing explanations of these accounts). Finally, a line of argument synthesis combined these themes to arrive at inferences, based on our interpretative account, about the phenomena being reviewed.

Quality assurance

To ensure the overall quality of the review, we were guided by the framework proposed by Patton (1999). (i) We followed a rigorous procedure for data identification through a systematic search strategy. (ii) Data analyses were conducted by two independent researchers who were not involved in previous research in this area (researcher triangulation). (iii) Credibility of the analyses was enhanced by testing rival explanations and undertaking negative case analysis. (iv) Transparency was enhanced by providing direct quotes from the primary papers to demonstrate our interpretations.

Results

Our synthesis of five papers was based on data from 87 participants. The studies were from the UK and Sweden. All of the studies were mixed aetiology. Studies employed thematic analysis (das Nair & Lincoln, 2013), comparative analysis (Nilsson, Bartfai, & Lofgren, 2011), framework analysis (Spector, Gardner, & Orrell, 2011), and content analysis (Johansson & Tornmalm, 2012; Lexell, Alkhed, & Olsson, 2013).

A summary of the CASP ratings is shown in Table 2. All included studies reported a clear statement of aims and utilised a methodology and research design appropriate to address these aims.

Furthermore, all studies reported a clear statement of findings.

Table 2

All the studies, with one exception (Spector et al, 2011), had an appropriate recruitment strategy. In this study, the sampling strategy and the number of people that declined to take part was not

mentioned; therefore, it was not possible to determine whether the recruitment strategy was appropriate. One study did not explicitly list a topic guide for the interviews and there was no discussion of saturation of data (Johansson & Tornmalm, 2012), consequently it was unclear whether the data were collected in a way that addressed the research issue. In three of the studies there was no mention of ethics approval (Johansson & Tornmalm, 2012; Lexell et al, 2013; Nilsson et al, 2011) and one study (Johansson & Tornmalm, 2012) omitted details regarding the consent process. This study also provided insufficient detail of the rigour of the data analysis; however, the remaining four studies gave sufficient detail. The relationship between researcher and participants was not explicitly considered in any of the studies. Where the feedback interviews were part of a nested study within a RCT, no details were given about the relationship between the researcher who conducted the interviews and their role within the rest of the trial (das Nair & Lincoln, 2013). Despite these limitations, all included studies were deemed to be valuable in providing rich qualitative data.

In synthesising the themes from the five studies, we arrived at five higher order themes. In all but one of these themes, we delineated subthemes, which described related but different aspects of the same broader theme. Each of these themes and subthemes are described below (see table 3 for a summary of the themes and which papers endorsed these).

Table 3

1. Insight and acceptance

Evidence for this theme was derived from three studies, which described how participants felt that they were able to begin to recognise and understand their cognitive problems; and then address these cognitive problems in daily life.

(i) Connecting cognitive deficits with daily problems: Prior to attending the groups, people may have identified cognitive problems but may not have made the connection between their cognitive deficits and their everyday problems.

“Training has made me realize that I really have brain damage and that it causes a lot of the trouble I experience daily”. (Johansson & Tornmalm, 2012, p179).

“That I almost thought was the worst thing, for such a long time thinking that, not knowing what it was all about, not understand that... I felt mentally ill. I started to think that I was work-shy, or did not want to work. No, but you need to hear what has really happened”. (Nilsson et al, 2011, p973)

As can be seen from these quotes, participants who did not make this connection between their neurological condition and resultant cognitive deficits, and the impact this had on their daily life, struggled to make sense of their day-to-day problems. Without making this connection, participants made interpretations of their failures (e.g., “I felt mentally ill”; “I started to think I was work-shy”) (Nilsson et al, 2011, p534) which could be stressful. However, with making this connection, participants were able to move forward to deal with the problem more actively.

(ii) Taking control of cognitive problems: This subtheme captures the active role participants played in dealing with their cognitive problems.

“...it's [attending groups] made me more open, when I get stuck with words, I just say, 'I'm very sorry, my brain's not functioning', whereas before I'd just get very...umm...frustrated”. (das Nair & Lincoln, 2013, p534).

“I've also learned to do... I should never just think I can do something without reading the instructions because I always used to do that. Whereas now I read the instructions

because... if you make a mistake when you do it first time it stays in your head. So I don't do that now". (das Nair & Lincoln, 2013, p536).

In both these quotes, participants demonstrated a change in attitude (e.g., "made me more open") and a strategy for dealing with the problem (e.g., using a particular phrase to explain a challenge, or changing the way they do things now). The *change* reported in both participants, as a result of attending the groups, is observed in the language they used (e.g., "...whereas *before*..." and "...I don't do that *now*").

2. Therapeutic effects of a group

This theme related to both the social support participants received from group members, but also the leisure activity that the groups afforded.

(i) Social support: The group was a safe space for people to share the problems they experienced as a result of their cognitive problems or their neurological condition.

"... it felt good to talk to the others in the group because we shared a similar experience... you could tell them about your problems, if you didn't remember, how you felt and then you ask what they think and how they feel. It's good because you know you are not weird in any way... we got to know each other really well... about everything in life, and then you saw things that others didn't see and maybe gave and took help in different ways and learned things yourself... we helped each other, not as with a family member... you felt safe with the [other members of the] group". (Lexell et al, 2012, p533).

"Yes the trouble shared is a trouble halved as they say, yes, you think there's other people out there and geographically not far away could be next door, So yeah I think it helped all of us to know that we're on the same boat on the same road, yes that was a very good part of it". (Spector et al, 2011, p947)

“[You] sit in a group, say something, and the other people in the group will say back to you... ‘Oh I get that’. It was quite nice. I suppose it just puts your confidence up that you’re not the only person that does brain- dead sort of things”. (das Nair & Lincoln, 2013, p540).

The groups gave participants opportunities to see that there were others like them (“...know you are not weird...”). This normalising experience through shared experiences can itself be therapeutic and affirming for some individuals (Wilson, 2009).

(ii) Leisure: Social isolation following ABIs is common (Hammell, 1994). Participants appeared to have attended the groups not only for the potential benefits of *cognitive* rehabilitation, but also to meet other people.

“It gave me somewhere to go. I did enjoy coming to the sessions. I did enjoy meeting one or two people, one of whom I am still in contact with”. (das Nair & Lincoln, 2013, p540).

For some it was “the highlight of the week” (Johansson & Tornmalm, 2012, p181) and the groups were seen as “fun” and “enjoyable”, with “an awful lot of laughing” (Spector et al, 2011, p947).

3. Improvements in memory

For many studies, improving memory (or more accurately, reducing forgetting) was the primary aim. There were three subthemes related to this improvement, in terms of knowledge gained, skills and strategies learnt, and the positive impact of the intervention.

(i) Knowledge gained: Most people felt that they had gained a deeper understanding of their memory problems. This was achieved in two ways: (a) in the form of the brain-behaviour connection:

“... it really make[s] sense because sometimes now I tend to visualise what’s happening in my brain. And if it’s actually gone somewhere and stored. Or whether it’s gone here and gone straight out... It actually is amazing to sort of visualise what your brain’s doing ’cos you don’t think about it until somebody points out to you that your brain’s actually like a great huge filing system. And that was actually quite interesting”. (das Nair & Lincoln, 2013, p535).

Or (b) in the form of self-awareness of what “works” for them:

“I need a clear list of instructions to be able to manage an activity in several steps”.

(Johansson & Tornmalm, 2012, p180).

However, not everyone benefitted from sessions where information about these two aspects was imparted, particularly in relation to the more didactic initial sessions:

“... because I think that [session] was more technical. And my brain didn’t absorb it all to be honest”. (das Nair & Lincoln, 2013, p534).

(ii) Skills and strategies learnt: Participants developed specific skills and deployed strategies to help them cope with their daily memory problems:

“My manager [a calendar] tells me what to do, it is a colourful, rather thick book. The text on the front reads manager. It’s easy to find, it’s difficult to mislay, and I have a special place for it as well. I write in it as a diary... and note things I need to do, like clipping my toenails, [...] I write the date and then I cross over when I’m finished... it’s a great help. I notice that if I don’t use it [the calendar], I get more tired and things get more confused and I don’t get as many things done as when I use it”. (Lexell et al, 2012, p532).

“...now that I can actually think which one [strategy] shall I use, which is the best one to use, because I’ve been given names as such. So it’s easier for me now to pull in a particular

strategy... sort of a tool from my toolbox to use which is appropriate for me for that particular task. So yeah, I'd say I'm a little more maybe organised". (das Nair & Lincoln, 2013, p535)

(iii) Positive impact of the intervention: For many, the intervention appeared to have had a positive effect. Forgetting was reportedly reduced in social interactions (e.g., remembering the name of their doctor or the rules of a card game [Johansson & Tornmalm, 2012, p180]) and "... remembering the recent events have been a lot more simple and a lot more logical than it was, certainly." (Spector et al, 2011, p948).

4. Other psychological effects

For many participants, it was not only improvements to their memory that they observed, but psychological effects were also reported.

(i) Mood: Many felt that the rehabilitation, and resultant improvements in memory, had reduced distress.

"I'm a lot more relaxed. I could worry for England, or used to be able to worry for England. I probably still do, I don't know. But I do feel as though I'm a little more relaxed". (das Nair & Lincoln, 2013, p538).

"Now I know why I went from one room to another. I'm less stressed". (Johansson & Tornmalm, 2012, p180)

However, not everyone benefited in this respect. For the following individual, for instance, they felt that the intervention had come "too late" in their life post-injury:

"I wouldn't say that I noticed any difference in my mood as a result of the classes. I think for me in my personal circumstances the classes were a bit too late... I had already looked up and had tried a lot of different learning methods..." (das Nair & Lincoln, 2013, p538).

(ii) Fatigue: Perhaps as a result of reduced everyday memory failures which resulted in better planned activities, some people found that the rehabilitation had a positive impact on their levels of fatigue:

“I’m less tired and more alert”. (Johansson & Tornmalm, 2012, p181)

However, this benefit was not reported by all. In fact, some felt that the rehabilitation programme made them *more* tired:

“I get very tired and I need to sleep the whole day after a training day”. (Johansson & Tornmalm, 2012, p181)

“At the beginning of the week I manage more at work, towards the end I’m totally fixated on when I can go home and sleep”. (Nilsson et al, 2011, p974).

This suggests that activity monitoring should be carefully considered when developing and delivering memory rehabilitation for people with neurological conditions.

(iii) Confidence: For many participants, rehabilitation offered them the confidence to try new things without worry of forgetting:

“Now I dare go for a walk, I think I can find my way back”. (Johansson & Tornmalm, 2012, p180).

“... I have started to do other things that I haven’t done before, because I have got more confidence... ahhh... and I have got more confidence that I can remember things a bit easier than I used to”. (das Nair & Lincoln, 2013, p539).

Some participants made the connection between their lack of confidence and how this related to their mood, and ultimately their perception of their memory ability:

“...I tell you, the biggest thing is confidence. Because it really was upsetting me and I really did think it was worse than probably what my memory is really. My husband can’t get away with fibbing any more...” (das Nair & Lincoln, 2013, p538).

5. Impact on daily life

Improvements seen in memory function, mood, and confidence appeared to have a knock-on effect on participants’ personal, interpersonal, and professional lives.

(i) Personal: From a personal perspective, participants appeared to have an altered perspective on their life, in terms of how they saw themselves and their attitude to others. They felt more able to accept their limitations and attempt to work on the things that they could change.

“I do see life in a different way now. I can go out in the street knowing that it’s just... ‘It’s only a blip, get on with it’”. (das Nair & Lincoln, 2013, p539).

“It has made me think, ‘Well perhaps some things you cannot change and you have got to live with it and some things you can change and you have got to work at it’”. (das Nair & Lincoln, 2013, p539)

“I have a totally new job... a much cooler attitude to work; I found my capacity quickly, and don’t try to expose myself to a load of things I cannot complete.” (Nilsson et al, 2011, p975).

(ii) Interpersonal: Participants had to negotiate and accommodate to changes in their relationships with family and friends. They also had to alter their position in these relationships given their memory problems.

“... among friends I have always been considered as the person who can fix and arrange things, I still do that but not as much...at home my wife takes a greater part but we also divide

things more between us. We learned that during the rehabilitation programme”. (Lexell et al, 2012, p533).

“At home we use a calendar where we put all our [activities in]... what I’m doing, what my husband’s doing, what my son’s doing... and that was a bit half-heartedly being done but the session’s sort of shown me that it’s a good thing to have... because it does prevent arguments and unnecessary stress in the house”. (das Nair & Lincoln, 2013, p536).

Using the strategies learned during the sessions and an improved awareness of their limits enabled participants to organise their involvement with others better and engage more fruitfully in these interpersonal contexts.

(iii) Professional: Being in gainful employment was important for some people. Some saw their ability to be employed as a measure of their recovery, and actively sought to do what they felt was the right amount of work.

“It was a sort of measuring device. If I can work full-time, then I’ve recovered”. (Nilsson et al, 2011, p975).

“Work means a lot; that’s why I fight for longer hours; if I work less I cannot be involved in the same way”. (Nilsson et al, 2011, p975).

Discussion

This meta-synthesis examined patients’ perspectives of a group-based memory rehabilitation programmes for people with neurological conditions, by synthesising findings from five qualitative studies. While the primary outcome of effectiveness studies in memory rehabilitation has traditionally been memory function, our synthesis revealed that the perceived benefits are varied, and that impact on memory function is only part of a larger picture. Conducting such a meta-

synthesis allows us to generate some hypotheses about the psychological *processes* accompanying some of the changes people experience. This is a unique contribution of meta-syntheses of qualitative studies. However, we would like to present a caveat before discussing the results. The majority of the qualitative studies we found and included in this review did not include information that is considered important to the robustness and validity of qualitative research (see for e.g. Mays & Pope 2000). Information such as sampling strategies, audit trails, reflexivity of the account, etc. were missing from several papers. It is beyond the scope of this paper to speculate the reasons for this. However, the issue of whether to apply a strict quality threshold when considering inclusion of studies to a meta-synthesis is debated. Mays and Pope (2000) feel that it would be “unwise to consider any single set of guidelines as definitive” (p52). Searle (2000) too warns of falling into the trap of ‘criteriology’, of trying to specify criteria for judging the quality of qualitative studies. The reason we highlight this issue of quality here is to suggest that the results and ensuing discussion is therefore limited by the quality of the original papers.

The first theme focussed on insight and acceptance. Participants reported that they felt they gained a better understanding of their memory deficits through the intervention. It follows that without insight or acceptance of a deficit that someone is unlikely to work towards change, and previous research has shown a correlation between insight and intervention effectiveness (Joosten-Weyn Banningh et al., 2011). Whilst reviews of interventions to improve memory function have shown no evidence of effectiveness (Brissart et al., 2011; das Nair et al., 2012; O'Brien et al., 2008), insight could be an important precursor to improvements. The relationship between insight and participant perception of improvements in memory could be further explored in future research to better understand this interaction.

Group-based interventions have been reported to be therapeutic (Gauthier, Dalziel & Gauthier, 1987; Verhaeghen, Marcoen & Goossens, 1992). Both social support and leisure have been found to be important predictors of good quality of life in people with neurological conditions (Jorge et al.,

1993; Motl, McAuley, Snook, & Gliottoni, 2009; Tsousides & Gordon, 2009). Groups offered normalising experiences and helped build confidence. From a psychological perspective, feedback and positive reinforcement play a significant role in confidence building (Cicerone et al., 2000). The feedback from this review supported such research findings and highlighted the therapeutic nature of groups alone, regardless of group content.

The third theme highlighted was perceived improvement in memory. The groups gave participants an opportunity to learn about how memory works, which helped participants to develop skills and strategies to target their individual memory deficits. Participants reported they gained a 'toolbox' of strategies and could pick those that were most appropriate for each situation. However, not all of the feedback was positive. Some participants felt there was an information overload. This highlights a criticism of group interventions, as there is often a mixture of individuals' cognitive abilities as well as levels of deficit. It follows that if someone has very severe memory deficits they may not be able to absorb all of the information and retain this, whereas others may feel the pace is about right for them. This shows the necessity of adapting groups to individuals, as well as the possibility of grouping participants on level of deficits and/or cognitive abilities to take in and retain information. Participants reported other psychological effects of the group intervention. These were effects on mood, fatigue and confidence. There were both positive and negative effects on mood and negative effects reported. One individual reported the intervention was too late in terms of their recovery. It could, therefore, be that the possible positive or negative effects could be related to time post-injury/onset of their neurological disorder. Further research is necessary to explore this mediating variable. The effect of the intervention on fatigue was also mixed, with participants reporting both more and less tiredness, as a result of attending the groups. It would be interesting to see whether those with degenerative disorders differ in terms of fatigue from those with TBI or Stroke. It could also be that level of deficits or physical disabilities caused by the neurological disorder made an impact on fatigue. However, the generally positive effects reported by participants are not

unsurprising given the association between mood and cognitive functions reported by previous research (Ashby, Isen, & Turken, 1999; Montenegro et al., 2013).

The final theme relates to the impact the intervention has made on participants daily life. The quotes show participants' adjustment to their deficits in terms of making adaptations to their lives and relationships. Employment was shown to be an important marker of improvement, which is supported by research showing this to be a common goal of rehabilitation (Saltychev, Eskola, Tenovuo, & Laimi, 2013).

The findings of this meta-synthesis of studies should be viewed in context of the limitations of the review. Although we employed a systematic search for all relevant studies, there is always the possibility that relevant studies have been missed. There is also the possibility of publication bias, meaning only those studies with positive outcomes of memory rehabilitation were published. Whilst we attempted to include negative quotes when they were reported, these were infrequent. It could be that there were just very few 'negative' comments or it could be that these were under-reported in the original studies. If full transcripts of interviews/focus groups were available, this would have been clearer and the review more controlled. Similarly, not all of the papers reported the full interview schedules and therefore it is hard to know what questions were asked and how these may have influenced participants' responses. Again, this would have given the quotes more context and ensure these were not misreported.

Whilst it is difficult to identify the processes of change behind the outcomes highlighted, these could be further explored if the interview/focus group questions were reported. Perhaps more focussed questions would elicit more information regarding the processes of change. In terms of what papers reported, whilst the studies included were mostly of high quality, none of the studies reported the relationship between the researcher and the participants. For example, was the interviewer involved in the intervention? This could have created a bias, as participants may have been less likely to

report negative experiences; however, this remains unclear as the papers did not provide this information.

One interesting aspect of studies that require participants with memory problems to recall their experiences is the 'truth' of those claims. Paterson and Scott-Findlay (2002) have explored these issues in detail, and have proposed ways of interviewing people with cognitive disabilities. Carlsson, Paterson, Scott-Findlay, Ehnfors, and Ehrenberg (2007) have identified strategies to address methodological issues related to sampling, consent and fatigue. This was specifically for participants with communication difficulties following an acquired brain injury. However, others have similarly conducted studies with participants with intellectual difficulties e.g. Gilbert (2004) and dementia e.g. Moore and Hollett (2003), which have led to suggestions for researchers conducting interviews with such participants. These suggestions included adaptations of interview schedules and styles. The papers included do not comment on how they had to adapt their interview schedules or techniques, if at all, for their data collection. Furthermore, some studies (e.g. das Nair & Lincoln 2013), did not include participants with communication difficulties. This, therefore, limits the generalizability of findings to those who may have been excluded for these reasons. Future studies that explicitly wish to consider the views and experiences of participants with cognitive difficulties, should consider ways in which they can collect such information, without having to exclude participants with such difficulties from their sample. This said, we acknowledge that some of these interview studies may have been done as part of larger RCTs, which have stringent inclusion/exclusion criteria, for example for the use of standardised assessment measures that may exclude participants with certain cognitive difficulties (e.g. difficulties with speech and language).

There were few studies found that satisfied the inclusion criteria for this review; more studies are necessary to further explore the findings. Specific aetiology-related effects of rehabilitation were not explored in this review, and there could very well be differential effects for those with degenerative conditions compared to sudden onset neurological disorders. Despite these limitations, this review

highlights the importance of group-based memory rehabilitation and the significance of incorporating well-designed and well-reported qualitative studies within more traditional methods of evaluating effectiveness of memory rehabilitation programmes. Whilst improvements in memory following group-based interventions have shown mixed evidence, this review highlights the largely positive impact of these interventions for most of the participants involved.

Conclusions

Meta-synthesis offers a unique possibility of systematically combining qualitative research literature to offer new insights about a phenomenon. Qualitative studies can help us better understand patient perspectives of interventions and their perceptions of how such interventions may or may not have impacted their wellbeing. We would therefore endorse their use in RCTs of memory rehabilitation. However, the quality of some qualitative studies in cognitive rehabilitation literature is poor, and authors should consider providing information that would tap into some quality criteria for qualitative studies. Our study investigated the perceived effects of attending a group-based memory rehabilitation programme for people with neurological conditions. Participants reported improved ways of coping with their memory problems and they felt rehabilitation had positively affected their mood. We hypothesise that group interventions led to better insight and acceptance of their neurological condition and resultant impairments. Group settings, may offer a safe space for patients to share their concerns, develop and test new skills, and improve confidence. These changes ultimately had a positive impact on participants' daily lives through improvements in their personal, interpersonal and profession lives. Therefore, this synthesis of qualitative studies suggests that memory rehabilitation offers positive outcomes for people with long-term neurological conditions, but these need to be considered in light of some of the limitations of the studies included in this review.

Disclosure Statement

RdN was the co-author of one of the papers included in this review.

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Appendix a; MEDLINE Search Strategy

1. (narrative approach* or life-story or narrative analys* or semi-structured or semi structured or interpretative or phenomenolog* or focus group\$ or interview\$ or discourse analys* or discursive or conversational analys* or grounded theory or qualitative or content analys* or thematic analys* or perspective\$).tw.
2. brain injuries/ or head injuries, closed/ or head injuries, penetrating/ or intracranial hemorrhage, traumatic/
3. brain injuries/ or diffuse axonal injury/
4. exp stroke/ or brain infarction/
5. Anoxia/
6. demyelinating autoimmune diseases, cns/ or multiple sclerosis/ or multiple sclerosis, chronic progressive/ or multiple sclerosis, relapsing-remitting/
7. dementia/ or alzheimer disease/ or dementia, vascular/ or huntington disease/ or lewy body disease/
8. Epilepsy, Partial, Motor/ or Epilepsy, Temporal Lobe/ or Epilepsy, Complex Partial/ or Epilepsy, Partial, Sensory/ or Epilepsy, Reflex/ or Epilepsy, Benign Neonatal/ or Epilepsy, Tonic-Clonic/ or Epilepsy, Post-Traumatic/ or Epilepsy, Frontal Lobe/ or Epilepsy, Absence/ or Epilepsy/ or Epilepsy, Rolandic/ or Epilepsy, Generalized/
9. Glioma/ or Astrocytoma/ or Brain Neoplasms/ or Glioblastoma/
10. Hematoma, Subdural, Intracranial/ or Hematoma, Epidural, Cranial/ or Hematoma/ or Hematoma, Subdural/
11. Intracranial Aneurysm/ or Aneurysm/
12. memory disorders/ or amnesia/ or korsakoff syndrome/
13. Encephalitis/
14. Meningitis/
15. Embolism/
16. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. (craniocerebral trauma\$ or acquired brain injur* or traumatic brain injur* or stroke or anoxia or hypoxi\$ or multiple sclerosis or ms or dementia or alzheimers or epilepsy or tumour\$ or h?ematoma or aneurysm or h?emorrhag* or encephaliti* or mening* or emboli* or amnesia or korsakoffs or neurological).tw.
18. 16 or 17
19. Rehabilitation/
20. Cognitive Therapy/
21. (neurorehabilitation or neuro-rehabilitation or neuropsychological or training or retraining or re-training or therapeutic\$ or rehabilitation or cognitive rehabilitation or therap*).tw.
22. 19 or 20 or 21
23. Group.tw.
24. (memory or cognitive or forgetting or cognition).tw.
25. 1 and 18 and 22 and 23 and 24

| Table 1; Data Extraction Tool | | | | | |
|-------------------------------|---------|---------------------------|--|--------------------------------------|--------------------|
| Study | Country | Participants | Aetiologies | Participants Age (years) | Method of analysis |
| das Nair & Lincoln (2013) | UK | n=31 24 women , 7 men | TBI (n=4) Stroke (n=6) MS (n=21) | Mean: 45 SD: 9.61 Range: 18-66 | Thematic |
| Lexell et al(2012) | Sweden | n= 11 6 women , 6 men | TBI (n=5) Subarachnoid Haemorrhage (n=3) Tumour (n=1) Stroke (n=1) Anoxic injury (n=1) | Mean: 45.2 Range: 25-62 | Content |
| Spector et al (2011) | UK | n= 38 12 women , 5 men | Alzheimer's (n=16) Lewy Body Dementia (n=1) | Mean: 82 | Framework |
| Johansson & Tornmalm (2012) | Sweden | n= 18 5 women , 13 men | TBI (n=5) Tumour (n=6) Stroke (n=7) | Mean: 47.5 SD: 13 | Content |
| Nilsson et al (2011) | Sweden | n= 10 5 women , 5 men | Stroke (n=4) TBI (n=4) Encephalitis (n=2) | Mean: 48.2 Range:22-59 | Comparative |

| Table 2: CASP quality assessment of included papers. | | | | | |
|--|----------|----------|----------|----------|----------|
| Question | 1 | 2 | 3 | 4 | 5 |
| Clear statement of aims? | Yes | Yes | Yes | Yes | Yes |
| Appropriate qualitative methodology? | Yes | Yes | Yes | Yes | Yes |
| Research design appropriate? | Yes | Yes | Yes | Yes | Yes |
| Recruitment strategy appropriate? | Yes | Yes | Yes | Yes | Unclear |
| Data collection sufficiently addresses research issue? | Yes | Unclear | Yes | Yes | Yes |
| Relationship between researcher and participants considered? | Unclear | Unclear | Unclear | Unclear | Unclear |
| Ethical issues considered? | Yes | Unclear | Unclear | Yes | Yes |
| Data analysis sufficiently rigorous? | Yes | Unclear | Yes | Yes | Yes |
| Clear statement of findings? | Yes | Yes | Yes | Yes | Yes |
| How valuable is the research? | Valuable | Valuable | Valuable | Valuable | Valuable |

1. das Nair & Lincoln (2013); 2. Lexell et al (2012); 3. Spector et al (2011); 4. Johansson & Tornmalm (2012); 5. Nilsson et al (2011).

Table 3: Thematic structure and papers endorsing each theme and sub-theme

| Themes & Subthemes | 1. | 2. | 3. | 4. | 5. |
|--------------------------------|-----------|-----------|-----------|-----------|-----------|
| Insight & Acceptance | + | + | | + | + |
| Therapeutic effects of a group | + | + | + | + | + |
| • Social Leisure | + | | + | + | |
| • Social Support | + | + | + | | + |
| Memory Improvement | + | + | + | + | + |
| • Knowledge | + | + | | + | + |
| • Skills & Strategies | + | + | + | + | |
| • Impact | + | | + | + | |
| Affective Changes | + | + | | + | + |
| • Mood | + | + | | + | |
| • Fatigue | | | | + | + |
| • Confidence | + | | + | + | |
| Impact on Daily Life | + | + | + | + | + |
| • Relationships | + | + | + | + | + |
| • Work | | | | | + |
| • Altered Perspectives of life | + | + | | | + |

1. das Nair & Lincoln (2013); 2. Lexell et al (2012); 3. Spector et al (2011); 4. Johansson & Tornmalm (2012); 5. Nilsson et al (2011).

Figure 1: PRISMA diagram showing the article screening process

