

REVIEW PAPER

Stroke survivors' and family members' perspectives of multimodal lifestyle interventions for secondary prevention of stroke and transient ischemic attack: a qualitative review and meta-aggregation

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Abstract

Purpose: The incidence of stroke is of global concern, and the rates of recurrence are high. Many risk factors are related to lifestyle behaviours and, as such, are amenable to change. Implementation of effective secondary prevention interventions is essential; however, little is known about influences on participation and adherence. This review and meta-aggregation aimed to improve understanding of stroke survivor and family member perspectives of secondary prevention interventions. **Methods:** We searched 11 databases, e.g. Medline and PsycINFO. We included qualitative studies that focused on adult stroke survivors and family members who had participated in a multimodal stroke secondary prevention intervention. Critical appraisal and data extraction were performed independently by two reviewers. A meta-aggregation of qualitative findings was conducted. **Results:** Five papers were included. One hundred and three findings were extracted and grouped into 14 categories from which three synthesised findings emerged: feeling supported, acquiring knowledge and gaining confidence. **Conclusions:** The findings highlight the perceived benefits of participation in secondary prevention group interventions from the perspective of stroke survivors and family members, i.e. feeling supported, by others with shared understanding and by knowledgeable health professionals, acquiring new knowledge and gaining confidence. These findings may be used to inform development of patient-centred interventions and thereby assist in improving health outcomes.

Keywords

Family perspectives, patient-centred, secondary prevention, stroke, survivor perspectives, transient ischemic attack

History

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► Implications for Rehabilitation

- Health professionals should consider implementing group-based secondary prevention interventions.
- The content of group-based secondary prevention interventions should be person-centred, i.e. meaningful and relevant to the individual.
- Stroke survivors and family members are more likely to comply with advice and information provided by expert and experienced health professionals.

Introduction

The high incidence of stroke is of global concern. Many of the causative factors are related to lifestyle [1] and therefore amenable to change. Similarly, high rates of recurrence of vascular events emphasise the important role of secondary prevention in stroke rehabilitation [2]. A growing body of evidence indicates that positively promoting risk factor management for people with stroke and TIA improves survival and lowers recurrence [3]. Although age is the single biggest predictor of stroke [4,5], there are many other factors that

increase likelihood of recurrence. These include inherent/non-modifiable factors, such as race or ethnic background, and modifiable risk factors, such as hypertension, abnormal blood lipids, being a current smoker, poor diet (e.g. high intake of saturated fats, low intake of fruit and vegetables), high alcohol intake, physical inactivity, abdominal obesity, diabetes mellitus, and psychosocial stress and depression [6]. International evidence-based guidelines recommend the implementation of multimodal secondary prevention interventions following stroke to reduce risk of recurrence of stroke or other vascular events [7]. Multimodal interventions promote appropriate prescription of combination therapy (antihypertensives, statins and antiplatelets), stroke and lifestyle education, including education regarding medication compliance, and strategies to support initiation and maintenance of positive changes to lifestyle behaviour(s) [8]. There is a strong evidence-base regarding the

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effectiveness of such programmes in specialties such as cardiology (e.g. [8,9]). For example, a cluster RCT, undertaken in 24 centres in 8 European countries found a family-based multimodal cardiology programme to be effective in helping people with/at high risk of cardiac disease and their partners improve their diet, increase their levels of physical activity and exert better control over their blood pressure [8]. Of note is the fact that the authors state that an important mechanism for change was active involvement of patients and their partners in the intervention; together couples made healthier food choices and became more physically active than previously [8]. Evidence in the stroke field exists but is weaker. Systematic reviews of multimodal stroke secondary prevention interventions have found “emerging” evidence of effectiveness in relation to increasing physical activity and improving dietary intake [10,11] and reducing blood pressure, cholesterol levels and Body Mass Index (BMI) [10]. Importantly, there is little evidence that assists understanding of how best to support stroke survivors to make healthy changes to lifestyle behaviours and thus help reduce their risk of recurrent TIA/stroke [12]. This is of concern as there is increasing recognition that health services should be responsive to the needs and priorities of service users and their families [13]. In the UK, for example, the Department of Health advocates a patient-centred approach to the design, development and delivery of health-care services [13]. This is in contrast to “traditional” approaches to care design and delivery, such as medical models, which adopt a paternalistic approach [14] and often result in tension between the aims and priorities of healthcare professionals, and those of patients and families accessing health-care services [15]. For example, Redfern et al. [16] found that healthcare professionals and patients had different priorities with respect to prevention of recurrent stroke, and tensions arose between healthcare professionals and patients whose views of the experience of stroke and stroke services differed. A recent mixed methods’ review found limited evidence of the acceptability of patient-centred interventions from the perspective of stroke survivors [17]. This represents an important limitation in the current evidence base, as gaining an understanding of survivors’ perceptions is an important and essential stage in the development of effective person-centred interventions which should, from design to delivery, reflect an understanding of, and a responsiveness to, the experiences and needs of recipients [16]. Our scoping searches revealed no syntheses of survivor or family perspectives of stroke secondary prevention initiatives. Such knowledge is essential to maximise participation and adherence [17].

Evidence-based healthcare practice has been conceptualised as clinical decision-making that considers the best available evidence, the context within which care is delivered, patient preference and the professional judgment of the healthcare professional [18]. The Joanna Briggs Institute (JBI) model of evidence-based healthcare describes four major components: evidence generation, evidence synthesis, evidence (knowledge) transfer and evidence utilisation [18,19]. Health professionals seek evidence to determine the worth of a wide range of activities and interventions and thus the type of evidence needed depends on the nature of the activity and its purpose. For example, systematic reviews and meta-analyses allow judgments to be made regarding effectiveness of interventions; however, they cannot answer the full range of questions posed by healthcare professionals [18]. Within the JBI model, four types of evidence are described: feasibility, appropriateness, meaningfulness and effectiveness (FAME). Feasibility is concerned with the extent to which an activity is practical and practicable. Appropriateness is the extent to which an intervention is apt in a particular situation. Meaningfulness refers to evidence that takes

the form of participants’/professionals’ views and experiences of interventions, including content and mode of delivery. And finally, effectiveness is the extent to which an intervention achieves the intended effect [18]. To answer a healthcare question relating to patient perceptions and patients’ experiences, as in the review reported here, a synthesis of qualitative evidence is required. Meta-aggregation, an approach to the synthesis of qualitative evidence developed by the Joanna Briggs Institute, is a pragmatic approach which, rigorously applied, produces methodologically sound syntheses that may be used to inform healthcare practice and service delivery [20]. Therefore, as part of the developmental phase of a programme of research into lifestyle behaviour change and stroke secondary prevention, which aligns with guidance from the Medical Research Council on the development and evaluation of complex interventions to improve health [21], we undertook a qualitative review. The review addresses the gap in knowledge highlighted above and aims to explore the experience of participation in a multimodal secondary prevention intervention, from the perspective of stroke survivors and family members. The new knowledge resulting from this qualitative synthesis will enhance the existing evidence base and inform current inter-professional clinical practice and development of patient-centred stroke secondary prevention interventions. The review findings will inform our subsequent secondary prevention work.

Methods

Literature search strategy

A comprehensive search strategy enabled identification of relevant studies. Eleven electronic bibliographic databases were searched, including: AARP (American Association of Retired Persons), Ageline, AMED (Allied and Complimentary Medicines Database), ASSIA (Applied Social Sciences Index and Abstracts), CINAHL (Cumulative Index to Nursing and Allied Health Literature), EMBASE (Excerpta Medica), ERIC (Education Resources Information Centre), HMIC (The Health Management Information Consortium), MEDLINE, PsycINFO and Social Work Abstracts. Search strings were developed using subject headings and keywords relating to stroke, secondary prevention and lifestyle behaviours, combined with Boolean operators and making use of search syntax, as appropriate to the individual databases. For example, MESH terms (Medical Subject Headings) included: “Stroke”, “Cerebrovascular Disorders”, “Ischemic Attack, Transient”, “Health Promotion”, “Secondary Prevention”, “Smoking”, “Tobacco”, “Exercise”, “Diet, Mediterranean” and “Diet, Reducing”. Keywords included: “stroke”, “CVA”, “transient ischemia”, “patient education”, “alcohol adj3 drinking”, “tobacco”, “physical exercise”, and “[diet\$ adj3 (fat-restricted or Mediterranean or reducing or diabetic)]”.

Reference lists of included papers were also reviewed, and key personnel/organisations, e.g. senior stroke professionals and voluntary sector stroke organisations, were contacted to identify any relevant grey literature.

Inclusion dates were from 1980 to 2014. Health promotion was formally acknowledged and defined as an important part of healthcare professionals’ work by the World Health Organisation in 1986, as part of The Ottawa Charter [22]. It was largely from this decade onwards that formal initiatives came into being and became the focus of empirical research. Therefore, studies dating from 1980 were included in the review. Other delimiters applied to the search terms included a focus on human studies and, due to resource limitations, studies reported in the English language. Web-based bibliographic management software, RefWorks™, was used to store and organise references.

Table 1. Screening for relevance: SPIO inclusion/exclusion criteria.

	Inclusion criteria	Exclusion criteria
Study design	Qualitative designs: any Mixed method studies where the qualitative data may be extracted	Quantitative studies Epidemiological studies Audit Literature reviews Clinical guidelines Discussion/opinion papers
Population	Adults (aged ≥ 18 years) Stroke survivors Family members of stroke survivors who participated in the intervention along with a relative who had had a stroke Stroke, i.e. ischaemic stroke, haemorrhagic stroke, subarachnoid haemorrhage, minor stroke, transient ischaemic attack Mixed populations where stroke data can be extracted	Other diseases/conditions As sole focus: carers/family members/family caregivers, health professionals
Intervention	Multimodal lifestyle behaviour change interventions designed to address the prevention of recurrent stroke Multimodal is defined as an intervention which comprises 3 components: (1) medication education and/or medication compliance education; (2) education or active* information provision; and (3) one or more “behaviours” (defined below) *An intervention is classified as active if, following the provision of the information, there is a purposeful attempt to allow the participant to assimilate the information and a subsequent agreed plan for clarification and consolidation or reinforcement [42] Participants’ experiences of interventions such as those described here should be the focus of the data collection	Passive information giving/advice Public health/primary prevention initiatives and interventions Pharmacotherapy (as sole focus)
Outcomes	The findings, e.g. themes or categories, as reported by the author(s), constitute “outcomes”, and may include information about: Lifestyle: behaviour change re tobacco use, alcohol consumption, diet, physical activity; psychosocial stress, medication compliance Psychological outcomes: wellbeing; life satisfaction; Quality of Life (QoL); self-rated health Learning outcomes: knowledge of: signs and symptoms of stroke, appropriate response, risk factors; health-related attitudes &/or beliefs	Public health outcomes As sole outcome of interest: functional/motor rehabilitation outcomes, QoL, return to employment, social functioning/participation, mood disorders

Study selection

Following removal of duplicates, titles and abstracts were screened for relevance to review criteria. Full text papers of studies remaining in the review were then screened independently by two reviewers (of ML, JP, SK and JB), using pre-defined inclusion/exclusion criteria relating to study design, population, intervention and outcomes (SPIO) [19] (Table 1). Briefly, studies were included if they reported qualitative findings and focused on adults who had experienced a stroke or TIA and had participated in a multimodal secondary prevention intervention, with or without an accompanying family member or family carer.

Data extraction and synthesis

Data regarding study design, participant characteristics, intervention details and qualitative findings were extracted from the papers and recorded using a data extraction tool designed specifically for this review. Extracted data were entered into an evidence table, and all the authors were contacted by email to request missing information.

Qualitative data were synthesised using meta-aggregation, a method of synthesis of qualitative review data developed by the Joanna Briggs Institute [19]. Using this approach, two reviewers working independently extract findings, defined as “conclusions . . . reported by the author of the paper, often in the form of themes, categories or metaphors” [19, p. 40]. The reviewers then agree a final list of extracted findings. The agreed findings are

aggregated into categories based on similarity of meaning. Subsequently, categories are synthesised to generate “synthesised findings”. To ensure credibility and dependability, an auditable trail is provided which enables the reader to understand how the synthesised findings were developed from the findings and enables the individual findings to be traced through to the final synthesised findings. The synthesised findings were developed by JP and ML, and then reviewed by the research team. Following team discussion, minor modifications were made and consensus reached.

Appraisal of methodological quality

Anticipating that our searches would identify papers reporting a diverse range of methodological underpinnings and research designs, we sought a generic quality appraisal tool. We selected the CASP (Critical Appraisal Skills Programme) Qualitative Checklist, a validated tool used widely in qualitative research. The checklist comprises 10 items framed as questions. Possible responses are “yes”, “can’t tell” or “no”. Using this tool papers are “scored” out of 10. We selected a score of 6 as indicative that a paper was of sufficient methodological quality to merit inclusion in the review. This ensures that the review draws on the best available evidence. Two reviewers (of ML, SK and JB) independently appraised each paper and then met to agree their assessment. The outcome of the appraisal process is presented in tabular form, below.

Results

Following broad screening of 9124 bibliographic references (title and abstract, where available; published and grey literature), 96 papers were assessed for eligibility using the review SPIO criteria (Table 1); 5 papers [23–27] met the criteria.

Study characteristics

All five papers reported qualitative findings, which related to specific stroke secondary prevention intervention studies. Three studies were conducted in the UK [23–25], one in Canada [26] and one in Australia [27]. The number of participants ranged from 9 to 22, with a total of 84 participants across the five studies. Across the studies reporting mean age, the mean age of participants was 66 years. Where reported, time post-stroke of participation in relevant secondary prevention intervention (as opposed to participation in the qualitative study) varied widely: 1–15 months [25], ≤ 3 months [24] and 6–7 months [23] and 2 years (mean) [27]. Further detail of the included papers is provided in Table 2. Where reported, time of participation in qualitative interviews post-intervention also varied: “following completion” [27], 1 month [23], 3 months [26], 3–10 months [24].

Interventions

All five interventions were community based. An adapted comprehensive cardiac rehabilitation programme, consisting of weekly group exercise and education, was delivered in two local health centres and ran for 6 weeks [23]. ASPIRE (acute stroke, support to self care, secondary prevention, information, rehabilitation, and exercise) provided a group-work and exercise programme delivered in a hospital outpatient department; participants attended weekly for 12 weeks following discharge from hospital [24]. An unnamed intervention involved an 8-week community-based exercise and education programme with peer group support [25]. MOST (Moving On after Stroke) involved delivery by videoconference (to a community centre) of a 9-week stroke education and exercise self-management programme [26]. Masterstroke comprised weekly exercise and education classes delivered in a rehabilitation centre on a hospital campus, for 9 weeks [27].

Accessibility and inclusion

In terms of accessibility and inclusion, important issues when considering this population, all of the interventions required participation at a venue outside the home and, consequently, excluded people who were unable to access the venue and/or make their own transport arrangements.

Two studies [24,25] included people with mild communication deficits, but no details were provided regarding use of supportive communication tools or methods, therefore it is difficult to understand how meaningful inclusion was facilitated; stroke survivors with severe communication problems were excluded from two studies but they did not report whether people with communication impairments were included in their sample [23,27]. Taylor et al. [26] did not report on this issue. Two studies included people with mild cognitive deficits; two studies did not report on cognitive impairments [25,26]. Two studies [23,27] excluded people with severe cognitive impairment, but did not report whether people with cognitive impairment were included in the study. Taylor et al. [26] did not report on this issue.

Family involvement

With regard to family involvement, two studies [24,26] reported involvement of family members/carers, although little detail is

provided regarding the nature of that involvement, and family members are not well represented in the reported findings.

Quality

Four studies [23,25–27] were awarded 8 out of a possible 10 “yes” responses; one was awarded 6 out of a possible 10 “yes” responses [24]. As indicated, in Table 3, three papers [23,24,27] did not include a discussion of the role of the researcher, and any attempts to counter, for example, the potential for the researcher to bias and influence data collection, if appropriate to the methodology. Three papers [23,26,27] did not make clear the “value” of the research, e.g. in terms of its contribution to existing knowledge and understanding, or its transferability to other populations. Full details of the quality assessment are provided in Table 3.

Qualitative synthesis

One hundred and three qualitative findings were extracted from the papers and grouped into 14 categories. These categories were then merged to create three synthesised findings: *Feeling supported*, *Acquiring knowledge* and *Gaining confidence*. To aid the reader’s understanding of the analysis process and to provide an auditable trail, the 14 categories and their associated descriptions are presented in Table 4, along with the findings that contributed to their development. In Table 5, synthesised findings and their associated descriptions are presented along with descriptions and the categories from which they were developed.

Each synthesised theme is described below and evidenced using illustrative verbatim quotes extracted from the papers, which reflect the perspectives of stroke survivors and family members. Square brackets are used to indicate where text has been inserted to aid the reader’s understanding.

Feeling supported

Feeling supported was a major theme. It encompassed a sense of being supported which derived from participating in a group comprised people with shared experiences, receiving ongoing support from family members and input from health professionals who were perceived as experienced and expert.

Participants described the perceived benefits of being in a group and having contact with others who had similar experiences and had shared understandings of the experience of having had a stroke and living with its consequences:

...that’s what I found most fantastic [about the MOST group]...I thought, you know, there’s other people out there that are going through the same thing as I’m going through and, I wasn’t alone in this thing. ‘Cause I had nobody here at home that I could talk to, that would understand [26, p. 9]

This shared understanding facilitated bonding and helped participants develop a better understanding of their own experience:

It’s talking to other people reinforces the fact that you’re not alone, other people know how you feel and, and it’s good to empathise. If you empathise with the person who’s saying, saying the same things you feel, it gives you a better understanding of how you feel. [24, p. 112]

For some, contact with group members following their stroke was one of the few social interactions they had:

[After my stroke] the only contact I had with any social side was the stroke project, which... was excellent [25, p. 22]

Table 2. Details of studies included in the review.

Study, date, country	Study design, sampling, data collection methods, timing	Participants number, stroke type, age, gender	Intervention type, setting, timing, duration	Key outcomes, findings, authors' conclusions
Hillsdon et al. [23], UK	Qualitative study complementing an RCT; convenience sample; semi-structured interviews; 1 month post-intervention (CCR)	22 participants; TIA or minor stroke (not specified further) Age (mean): 67 years Gender: M = 17; F = 5	(adapted) Comprehensive Cardiac Rehabilitation (CCR) programme (exercise and education): group work; no other details provided. Time post-stroke was not clear; duration not reported	4 themes: Information delivery, Social comparison, Psychological impact, Attitudes and actions regarding risk factor reduction. CCR had a positive effect on motivation to exercise. Information recall was poor.
Neal [24], UK	Qualitative; sequential sample; semi-structured interviews; 3–10 months post-stroke	12 participants; stroke survivors $n = 4$, carers $n = 2$, stroke survivor/carer dyads $n = 3$; stroke (not specified further) Age (mean): 67 years Gender: M = 7; F = 4	ASPIRE (Acute stroke, Support to self care, secondary Prevention, & Information, Rehabilitation, & Exercise): group-work; community based. ≤ 3 months post-stroke; weekly for 12 weeks	Two emerging themes: ability to self care; value of the group. The ASPIRE programme promotes mood, confidence and ability to self care; group essential in that process.
Reed et al. [25]	Interpretative phenomenological study; maximum variation sampling; semi-structured interviews; 15–40 months post-stroke	12 participants; stroke (not specified further) Age: $<60 n = 1$; 61–72; $n = 3$; 73+ years $n = 8$ Gender: M = 5; F = 7	A community-based exercise and education scheme.	Three themes: create a social self; responsive services; informal support networks.
Taylor et al. [26], Canada	Qualitative study using an interpretive methodology; purposive sampling; semi-structured interviews; 3 months post-intervention (MOST)	19 participants: 12 stroke survivors; 7 caregivers; stroke (not specified further) Age (mean): 66.2 years Gender: M = 10; F = 9	MOST project (Moving On after Stroke): Videoconference delivery of a self-management program to rural participants with stroke. Time post-stroke not reported; twice weekly for 9 weeks	To rebuild lives after stroke internal and external resources are required. Stroke-specific community schemes (external resource) can help meet information and support needs. Four themes: accessibility & distance; participation in discussion & exercise; experiences of group involvement; suggestions for improvement. Videoconferencing participation was valuable & increased accessibility; addressing video-conferencing limitations & local support may improve the experience for remote participants.
White et al. [27], Australia	Mixed methods study; convenience sampling; semi-structured interviews; ‘‘following completion of intervention’’	21 participants; stroke (not specified further) Age (mean): 66 years Gender: M = 16; F = 5	Masterstroke exercise and education programme; group work; community-based. 2 years post-stroke (mean); twice weekly for 9 weeks	Six themes: loss of roles; stroke onset/knowledge; benefit of masterstroke; motivation to modify lifestyle. Participants found a key benefit was the group-based nature of the program

Table 3. Quality appraisal (CASP qualitative research checklist).

Paper	Was there a clear statement of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was data collected in a way that addressed the research issue?	Relationship between researcher & participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Hillsdon et al. [23]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Can't tell
Neal [24]	Yes	Yes	Yes	Yes	Can't tell	No	Can't tell	No	Yes	Yes
Reed et al. [25]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes
Taylor et al. [26]	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell
White et al. [27]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Can't tell

Family members, where they were included in the groups, derived similar benefits – learning from other family members how they managed. They also gained an insight into the stroke experience, from the perspective of stroke survivors:

[My husband] thought [attending the intervention] was the best time for us. I couldn't talk to him about it because I couldn't speak, but he had to learn. He found the scheme was positive because he understood what I was going through [25, p. 22]

Stroke survivors felt supported by family members who helped provide motivation to make positive changes to change lifestyle behaviours:

Yeah that was a hell of an achievement [achieving a reduction in his cholesterol level], I couldn't have done that without [my partner] [24, p. 111]

Such support was particularly welcomed if the family member was perceived to be providing advice rather than instruction. Similarly, participants felt supported by knowledgeable, experienced healthcare professionals who provided information, advice, guidance and motivation. They appreciated this “non-directive” approach:

I thought the way it was conducted was very good actually. I had good encouragement but not too many “do this” and “do that” [24, p. 110]

That said, some preferred a more directive approach, particularly in relation to physical activity. For these participants, the health professionals provided the “push” or motivation the individual required to help them to make changes:

It was exercise [that] was what I wanted. I mean, [in the hospital]...they give you a list of the exercises...but you don't have time to do it. But when you go [to the group intervention]...you've got to do it. I think that's the important thing. They push you into doing it. And I've definitely come on since then [25, p. 20]

Exercising in a group was found to be motivating and provided a psychological boost, improving mood and enhancing self-esteem. Becoming aware of improvements in physical recovery inside and outside of the weekly class encouraged continued participation and was motivational for other participants, too:

It was fun, it was work, it was good fun doing the exercises. It was a laugh. And that's what boosted the morale – ‘I'm getting somewhere’ - that attitude. I thought it was wonderful [25, p. 21]

One of them [another stroke survivor], his walking from the first day to the last improved 100%. [27, p. 935]

For some participants, the weekly class provided structure and was one of the reasons participants (stroke survivors and family members) cited for wanting the class to continue beyond its planned duration:

[The classes] gave a point to our week for one thing...as I say, it gave a structure to our week [24, p. 113]

I was upset when it finished. I wanted to do more. I was really upset not to go on and on because I was doing well with it. I wanted to carry on. I missed [the instructors] because they taught me how to do things and that [was] important to me [25, p. 21]

Table 4. Categories: label and description.

Category label	Category description
Knowledge gain	Stroke survivors & carers/family members gained knowledge by attending the course (N; W; H); course reinforces current knowledge (H); (new) knowledge supports behaviour change (R; N; W); (new) knowledge that is perceived as relevant influences readiness to change/decision-making (R); gives insight into effects of stroke and thus improves mutual understanding between stroke survivor and carer/family member (R); increases ability to self-care (N); carer's/family member's knowledge helps them better support & motivate the stroke survivor (N); intervention supports knowledge retention (N); persisting in former health beliefs in spite of education course e.g. not accepting that changing lifestyle risk can reduce the risk of recurrent events, and ill-health is not preventable because of genes/family history); health professionals blame an individual's particular "vice(s)" (H); education (new knowledge) is not valued unless it is perceived as relevant (R)
Comparing yourself with others in the group	Stroke survivors perceive themselves to be lucky when they compare themselves with other group members & consequently they do not want to have another stroke & this in turn influences their behaviour/motivates behaviour change (H; W); sharing common experiences reduces feelings of isolation (W); encouraged & motivated by observing improvement in others (W); comparing yourself with others increases self-esteem & alters the individual's perception of self as "disabled" (R); comparing yourself with others boosts confidence (N)
Perception of severity/significance of the TIA/Stroke event	Some stroke survivors felt that they had been/were wasting HP time and NHS resources because they had made a quick "recovery" (failing to understand the severity/implications of the event) (H); other people "made a fuss" (failing to understand the severity/implications of the event because of their quick recovery) (H); need for follow-up TIA appointment (for reassurance) (H)
Shared understandings/reciprocal learning/motivation (stroke survivors)	Beneficial to talk with another person who understands & isn't part of family (H); learn from other people e.g. how they have "managed" (W; R; N); empathy (W; T); information sharing (T); bonding due to shared experiences (R); mutual understanding support & encouragement (R; N); carers/family members benefit: you're not alone; mutual understanding (N)
Benefits of exercising/participating in a group	Exercising in a group supports desire to continue to improve (R; W; N); exercising in a (social) group boosts morale (mood?) (R); exercising in a (social) group is fun (R); exercising in a group increases self-esteem (R); motivation & camaraderie (T); contributing to the group helps re-establish a sense of purpose (R); intervention is an opportunity to socialise (W; T); end of intervention ends social opportunities for some individuals (R); boosts confidence (N); weekly group gives structure to the week (purpose) (N); for some carers/family members the group is respite (N); carers/family members note that stroke survivors benefit from the group (social opportunity, improved mood, continued physical recovery) (N); need sufficient numbers (stroke survivors and carers/family members) to derive benefits of group participation e.g. socialisation (T x 2); not threatening/safe (T); stroke survivors notice improved levels of personal exercise & associated outcomes e.g. in activities of daily living (W); opportunity to make lifestyle changes (W)
Recurrence	Minor stroke is a prompt to make healthy lifestyle changes (H); fear of recurrence motivates behaviour change (W x 3)
Social participation in the group: barriers/facilitators	Barriers: comorbidities (W); flow of conversation is difficult to get "right" with VC (T); participants with no on-site support were concerned about discussing personal issues with the rest of the VC group (confidentiality) (T); lack face-to-face meetings (T x 2); lack of open mike (T); VC (T); awareness of sense of distance (T); difficulty following instructions/keeping up with the group (T); facilitators were not always aware of participants who were having difficulty following instructions/keeping up (T); VC camera focuses only on the speaker; this prohibits feeling involved in the "group"; participating in any joking asides etc. (T); recognition of the person is difficult if you haven't met face-to-face (T); VC connection not comparable with face-to-face – can't discern facial details and subtle expressions, body language and gestures (T); having both visual and audio connection is important (makes for an improved experience, even if the video quality is not high quality) (T) Facilitators: video-conferencing (VC) reduces the need to travel (T x 2); VC (facilitator) (T); a local site volunteer to set up the room for VC & do "warm up" also helped participants to feel "safe" (T x 2); VC (T x 2); Facilitators managed the group interaction(s) e.g. limited "side conversations" (T); VC helps recognition/building rapport/ "same room" (T)
Encouragement (provided by health professionals)	Source of motivation; "pushes" you (W); lack of motivation to change lifestyle behaviours, when there is no external prompt (W), hence desire for the intervention/support to continue (R); perceived need for experts (health professionals) to provide support and to "push" you (R); provide a safe environment in which to work on physical recovery (R); support provided by health professionals is valued because of their expertise (trust) (N); stroke survivors want support and advice from health professionals – not instruction (N); direction/instruction required, not advice (H) Exercising in an environment that is perceived to be "safe", because of the presence of/support provided by experts, helps stroke survivors to regain confidence and self-belief (R x 2);
Confidence	Stroke survivors want support and advice from carers/family members – not instruction (N); Family members play an important role (care; support) (N)
Role of carers/family members	Severe impairment limits ability to exercise (W); effects of stroke (e.g. memory impairment) inhibit knowledge acquisition (H)
Effects of stroke	Stroke survivors were helped to set measurable and achievable goals (W); common goal: physical recovery to improve functional ability (W); some stroke survivors had not achieved all of the goals set at the beginning – for some this was a cause for concern; others were motivated to keep trying (W); to support behaviour change (N), stroke survivors required goals to be person-centred i.e. personally relevant (R), realistic (N), measurable e.g. changes in diet led to a reduced dose of statins (N)
Goals	A positive attitude (& humour) drives recovery (N)
Positive attitude	Easier to maintain an exercise habit if you have resources &/or support readily available (W); people who had exercised prior to Masterstroke were more likely to exercise after Masterstroke (W) (prior habit; access to resources)
Factors influencing sustained (i.e. post-intervention) behaviour change	

Table 5. Developing synthesised findings from the categories.

Synthesised finding	Category
Feeling supported	Shared understandings/reciprocal learning/ reciprocal motivation (stroke survivors) Role of carers/family members Encouragement (provided by health professionals) Benefits of exercising/participating in a group Social participation in the group: barriers/ facilitators Goals Factors influencing sustained behaviour change (i.e. post-intervention) Effects of stroke (used twice)
Acquiring knowledge	Knowledge gain Perception of severity/significance of the TIA/ Stroke event Effects of stroke (used twice) Recurrence
Gaining confidence	Confidence Positive attitude Comparing yourself with others in the group

Others appreciated that the support provided by professionals initially would be withdrawn, and at that stage the individual would be better equipped to cope than prior to embarking upon the course. As this family member describes, from this perspective, discontinuation of support was viewed positively:

You need it, and then it gives you what you need, and then you kind of, you graduate from it [24, p. 115]

The opportunity to set measurable and achievable goals, guided by professionals, was welcomed as a means of supporting initiation and maintenance of positive changes to behaviour:

It [attending the intervention] spurred me on in that way, by seeing the, by measuring the improvement, you could get benefit from that. Yeah it generally gave me goals and it widened my horizons to getting me back to being fit [24, p. 110]

Setting goals in safe environment helped participants to understand that they did not have to achieve everything at once.

It's made things clearer in terms of what my goals should be and also not to expect as much, to take it slowly and steadily rather than expecting to, you know, do a few exercises and I'm back to normal [24, p. 110]

I think I'm on my way to it, I wouldn't say I've achieved it because I don't think [I have]... I think you've got to keep working at it [27, p. 396]

Although, as described above, most participants felt supported, a few described barriers to social interaction, including limited group numbers, a particular issue for some of the stroke survivors accessing MOST, the intervention delivered using tele-conferencing facilities:

I find it's funny if I'm here [at the local video conferencing point] and if you're way out there and someplace, you know, TV and all that... [it] feels funny talking to, you know, a TV?... talk to the TV and you wish you were there, sitting with all the [other people], seeing everybody [face to face] [26, p. 8]

Participants in MOST noted several additional barriers to group bonding and social interaction, these included maintaining the flow of conversation, difficulty following instruction and keeping up and the group facilitators' lack of awareness of this. The participant below described the experience of being a single participant at a remote sight:

If there would have been another person or two with me, at my meetings [pause] then, it would have been more of a shared experience I think [26, p. 10]

Acquiring knowledge

Acquiring knowledge encompasses gaining understanding of the significance of the stroke event and its subsequent effects, acquiring (new) knowledge of the causes of stroke and modifiable risk factors, receiving information and advice about healthy living, and understanding how and why changes to lifestyle risk factors may help prevent recurrent stroke.

Commonly, participants linked knowledge gains to information provided by a credible, trustworthy source, i.e. a healthcare professional:

The things you learn about diet and stuff like that was incredible [27, p. 395]

The professional chats about things were, were extremely useful... generally, you came away from each session with something. Every session helped in its own small way [24, p. 107]

Information provided by professionals also appeared to lend weight to discussions about changes to lifestyle behaviours and medication compliance between stroke survivors and family members:

I was interested in how many units of alcohol he [husband] should drink and what should be his diet and, you know, about the pills and that, I was interested. [The education sessions] gave me a bit of confidence and a bit of ammunition [24, p. 107]

Some felt that the educational component of their classes simply reinforced pre-existing knowledge; others found that the consequences of stroke, such as memory impairment, hindered knowledge acquisition, but most participants appeared to be engaged in new learning.

At an individual level, knowledge gain was important to most participants because it allowed them to understand what had happened to them and possible causes or contributing factors:

A clot in the carotid artery, it went to my brain and stuck somewhere and cut off all the supply of blood to that part of the brain and killed all the cells [24, p. 109]

It's amazing in hindsight you think, 'well yeah', I knew I wasn't, er, exercising enough, I knew I wasn't eating properly at times... [23, p. 850]

The acquisition of new knowledge concerning possible causes and possible consequences of TIA and/or stroke motivated participants to make positive changes to lifestyle risk factors to help prevent recurrent stroke:

I try and go to work with a lunch box, which I've never done before. You know, full of fruit and er, proper sandwiches and that sort of thing [23, p. 850]

As with *Feeling Supported*, opinions regarding the need for advice or for instruction and direction varied. Some participants articulated a need for the manner of education delivery and knowledge sharing to be more directive, at an individual level:

Yeah, I mean, if they turned round and said “You really, really ought to lose – er, to lose a little bit more weight” then, then I’d obviously do something about that. But, unless somebody specifically says it, well you feel... I don’t think I’m doing badly [23, p. 850]

Gaining confidence

Gaining confidence comprises overcoming fears, feeling encouraged and developing a positive mental attitude, and was seen by some as “key” to recovery. Some participants perceived they had gained confidence as a result of having overcome fears. The experience and expertise of health professionals inspired confidence and motivated participants to work towards recovery:

I think the ASPIRE group helped me, give me confidence by saying things like, you will do these things, you will get better. That was the reinforcing part of it, somebody being encouraging and saying you know... somebody... I mean your wife can be encouraging... [but] she doesn’t really know. But you get somebody who is in the know and when they say you WILL recover, you tend to rely on that and trust them, and sure enough, you do... the physiotherapist and the nurses... know about strokes, and they can drive a person onto, onto later recovery [24, p. 110]

Participants’ confidence also grew as a result of comparing themselves, usually favourably, with others in the group; they perceived themselves to be “lucky” and this encouraged them to achieve more:

It was certainly a confidence booster. Being round people you could compare [yourself to] and you got the encouragement from any of the staff there [24, p. 109]

I think basically, seeing people around you – it sort of, not sounding cruel, they’re worse off than you. Thinking, “I can do this”. It’s a bit spiteful to say – I can do this and you can’t. It’s only a thought in your mind [25, p. 21]

For some stroke survivors, the desire to avoid having another stroke and the attendant possibility of becoming more disabled was motivational. Participants adopted a positive mental attitude and elected to make positive changes to lifestyle risk factors:

I don’t want to have another stroke anytime soon so I’m gonna do the darn best I can to make sure I don’t [27, p. 935]

Participants perceived exercising within the safe environment of a group supervised by acknowledged experts as physically beneficial and as providing a boost to confidence levels:

I think it’s given me the courage to carry on. It’s given me the... it buoys you up. It buoys you up to say there is a future out there, you will get better and you will carry on and do the things... that’s what the ASPIRE has done to me [24, p. 114] I think meeting the people [was the best thing] [25, p. 21]

Observing improvement in other group members was found to be motivational and boosted morale; it supported development of a “positive mental attitude”, as described above. This positive,

optimistic outlook helped participants to alter their perception of themselves as “disabled”; rather, they could see the potential for continued recovery:

The exercise machine[s], they were incidental... the major part of [the group] was maybe to meet others and see how they recover, and you think, well if they can recover, I can recover [24, p.115]

The woman that was going to knit, you know, her aim was to start her knitting again. And you could see that she was quite pleased with herself... I, ah, consider that as a, a motivation for the group. Because... you know, that’s really positive [pause] “I can, I can feed on that. Good things are happening in my group” [pause]... it builds confidence I guess [26, p. 9]

Discussion

This article presents a meta-aggregation of qualitative data from studies that have examined stroke survivors’ and family members’ perspectives of multimodal secondary prevention interventions following stroke. Three synthesised themes are described, *Feeling supported*, *Acquiring knowledge* and *Gaining confidence*, which form a framework to support our understanding of stroke survivors’ and family members’ perspectives of meaningful participation in multimodal secondary prevention interventions. The review has also revealed the reciprocal and interrelated nature of the themes, and the mechanisms likely to result in behaviour change. For example, professional and peer support appeared to be important in helping stroke survivors to develop confidence. Increased confidence helped stroke survivors and family members transfer the knowledge they had gained into action, i.e. to make lifestyle changes such as improving their diet. In turn, making changes to lifestyle behaviours appeared to increase levels of motivation and/or confidence. The reciprocal nature of what was described fits with Bandura’s Social Cognitive Theory (SCT), a psychological model of behaviour and behaviour change [28]. SCT proposes that a person’s behaviour is influenced by environmental factors (e.g. other people’s behaviour, including support and encouragement and social/group norms), personal factors (e.g. levels of motivation) and attributes of the behaviour itself (e.g. physical activity). Central tenets of SCT include self-efficacy (an individual’s confidence in their ability to change a particular behaviour) and the value placed on the perceived outcomes or consequences of a change in behaviour (e.g. believing that stopping smoking will reduce risk of recurrent stroke). Another important concept discussed by Bandura is “behavioural capacity”, which refers to the knowledge and skills required to change a particular behaviour (e.g. how to eat healthily or drink alcohol within the recommended limits).

Of note is the congruence of the synthesised findings from this review with those reported elsewhere in the long-term conditions literature. For example, “social support” and “education and knowledge” were key themes in a recent synthesis of lifestyle change maintenance in participants with a broad range of cardiovascular conditions, including transient ischemic attack [29]. The theoretical focus in our synthesis aids understanding of the psychological processes (e.g. self-efficacy) that influence behaviour change, and indicates how healthcare professionals might best offer support. The review highlights the importance of the healthcare professionals being seen to have expertise and experience in order to be considered credible providers of both support and education and, in this respect, our synthesis adds a new depth of analysis and understanding to the pre-existing evidence base.

With regard to the synthesised theme *acquiring knowledge*, it is known that providing information to stroke survivors and

families is insufficient on its own to influence positive behaviour change [30,31]. The review emphasised that for interventions to be effective, they need to take account of individual knowledge and understanding, and be tailored to reflect the individual's needs and state of readiness to learn. In this way, a person can *gain confidence* in their ability to make healthy changes to lifestyle [30]. While the verbatim quotes provide qualitative examples of improvements in knowledge and confidence/self-efficacy following stroke, gauging self-efficacy in the context of other medical conditions is more frequently achieved through the use of standardised outcomes measures. However, currently available outcome measures validated with stroke populations, focus on physical ability, and psychosocial and daily living functioning [32,33]; none has a specific focus on the measurement of self-efficacy in relation to health behaviour change [34]. An appropriate tool is required to support health professionals in the delivery of behavioural lifestyle interventions, tailored to meet person-centred health needs and outcomes.

Our findings emphasise the importance of the stroke survivor *feeling supported*, not only through the support offered by professionals, but also that offered by peers and family members. Little research has been undertaken regarding the reciprocal benefits of peer support amongst stroke survivors and family members [35]; however, studies of other survivor populations, including survivors with long-term conditions, have reported a range of benefits from this type of support which include skill acquisition, increasing confidence and increased self-efficacy [36,37]. While studies have highlighted the importance of provision of support, our review has revealed the perception of the person *feeling supported* as the most crucial element of such programmes, and the foundation for acquisition of knowledge and gaining of confidence/self-efficacy. Feeling supported is dependent on the group approach and the benefits that accrue from the shared experiences. It is also a consequence of perceiving the healthcare professionals as knowledgeable and experienced and therefore credible.

The three interlinking and overlapping synthesised themes may be viewed as key elements of behavioural interventions that are perceived as acceptable and meaningful by stroke survivors and family members. Awareness of these elements may help healthcare professionals to select appropriate, supportive, behaviour change approaches [38] and may contribute to clinical and survivor-perceived effectiveness of behavioural stroke secondary prevention interventions. In future work, we will examine whether there is an association between these key elements and the quantitatively assessed effectiveness of lifestyle interventions. This approach has previously been used to good effect in the synthesis of evidence for asthma treatment, where qualitative findings were used to inform quantitative evidence [39].

Strengths and limitations of the primary studies

Synthesised findings from the primary studies augment the limited evidence base relating to survivor perspectives of stroke secondary prevention interventions. The diversity of the included studies, and the congruence of the synthesised findings with other recently published results, confirms the relevance and transferability of our results in terms of contemporary clinical practice. However, there were certain intervention design limitations within the primary studies. For example, the interventions did not utilise inclusive strategies such as ensuring the accessibility of intervention provision or the use of communication support, and therefore excluded stroke survivors with severe cognitive or communicative impairments. Guidance on such inclusion is available [40,41], but awareness may still be limited amongst intervention developers,

or the challenges posed may be too resource intensive for use in small-scale studies.

Two studies included family/carer attendance during the intervention, although the nature and extent of their involvement were not clear. Previous research has indicated that a family-centred approach, although beneficial to survivor engagement, may be missing from many interventions [17,42,43] suggesting an area for further research.

Limitations of the review

Although the review methods were designed to be as comprehensive as possible, database searches may still fail to identify all pertinent studies. Searches of grey literature repositories were therefore conducted, and electronic table of content alerts from key journals set up; relevant reference lists were also searched, and key individuals contacted, for further information about research that should be considered for inclusion in the review. Unfortunately, due to resource constraints (personnel and time), we were unable to extend the review to include papers written in languages other than English, which may have limited the scope of our findings.

The small number of included papers demonstrates the limited availability of evidence, making the pooling and dissemination of these results all the more important for guiding clinical practice. It also provides evidence that further research is needed.

Conclusion

This qualitative review and meta-aggregation of studies involving stroke survivors and family members, who had first-hand experience of multimodal stroke secondary prevention interventions, enabled development of three synthesised themes. The themes, *Feeling supported*, *Acquiring knowledge* and *Gaining Confidence*, constitute an overarching framework which describes a dynamic process in which links between the acquisition of knowledge and the provision of support assist survivors to develop the confidence to make positive lifestyle behaviour changes following stroke. This theoretically informed framework represents new evidence that may be used to inform rehabilitation care and development of person-centred secondary prevention interventions. By incorporating these key elements, health professionals may support stroke survivors and families to improve knowledge and understanding, build confidence, improve potential to engage in self-management, and to make and/or sustain positive behaviour change, and ultimately improve health outcomes.

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