



Hughes, S., Lewis, S., Willis, K., Rogers, A., Wyke, S. and Smith, L. (2017) The experience of facilitators and participants of long term condition self-management group programmes: a qualitative synthesis. *Patient Education and Counseling*, 100(12), pp. 2244-2254. (doi:[10.1016/j.pec.2017.06.035](https://doi.org/10.1016/j.pec.2017.06.035))

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The experience of facilitators and participants of long term condition self-management group programmes: A qualitative synthesis.

ABSTRACT

Objective: Our aim was to systematically review the qualitative literature about the experiences of both facilitators and participants in a range of group-based programmes to support the self-management of long-term conditions.

Methods: We searched 7 databases using the terms 'self-management', 'group' and 'qualitative'. Full text articles meeting the inclusion criteria were retrieved for review. A thematic synthesis approach was used to analyse the studies.

Results: 2126 articles were identified and 24 were included for review. Group participants valued being with similar others and perceived peer support benefits. Facilitators (HCP and lay) had limited group specific training, were uncertain of purpose and prioritised education and medical conformity over supportive group processes and the promotion of self-management agency and engagement. Overall, studies prioritised positive descriptions.

Conclusion: Group programmes' medical self-management focus may reduce their ability to contribute to patient-valued outcomes. Further research is needed to explore this disconnect.

Practice implications: This review supports broadening the scope of group-based programmes to foreground shared learning, social support and development of agency. It is of relevance to developers and facilitators of group self-management programmes and their ability to address the burden of long-term conditions.

1. Introduction

Self-management is promoted as a solution to the increasing burden of disability and demand for health care associated with the rise in prevalence of long term conditions [1-4]. Improvements in self-management are expected to improve health service utilisation and better enable people to 'live well' with long-term conditions [5, 6]. This paper focuses on group-based self-management programmes which are often proposed as a cost-effective and evidence-based approach to supporting people with long term conditions [7-11].

Definitions of self-management have evolved over time, with more recent definitions focusing on the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and the associated inherent lifestyle changes [12]. Alongside this, self-management support is defined as what healthcare professionals, healthcare providers and the healthcare system do to assist patients with managing their condition [13-16].

Group self-management programmes vary in their purpose and content [11, 17], often including educational components and support for making behavioural changes as well as some group interaction and peer learning. The most widespread group-based programme is the Stanford Chronic Disease Self-Management Program (CDSMP) which has been adopted in the UK, Europe, Canada and Australia [18]. This peer-led programme is reported to seek to increase individuals' self-efficacy to manage conditions [19-21]. The CDSMP facilitators' role includes programme delivery, managing group dynamics and modelling healthy behaviours [22]. Group programmes for self-management of individual conditions such as diabetes and chronic obstructive pulmonary disease (COPD) follow standards and guidelines from national and international organisations, [23, 24] [25] (see Appendix 1.). Importantly, contemporary principles emphasise a patient-focused, collaborative approach and self-management elements such as education, symptom management, skills development, psychosocial elements, problem solving, behaviour change techniques and exercise training [23-26]. Desirable facilitators' competencies include intervention delivery, understanding of

behaviour change techniques [25] expertise, communication skills, emotional support and a goals focus [23].

Studies seeking evidence of the effectiveness of group-based self-management programmes show mixed results with only relatively modest short-term improvements in outcomes and equivocal evidence in healthcare utilization and cost reductions [21, 27-29]. Some studies do not differentiate between group and individual delivery making it difficult to draw conclusions [30-32]. Few reviews have focused specifically on groups or non-experimental studies [33]. An exception is a recent qualitative scoping review of the psychological benefits of self-management group participation [34].

Criticism of group programmes has emanated from the UK and its CDSMP influenced, state funded 'Expert Patient Programme (EPP)' [8, 9, 35, 36]. Specifically, criticisms relate to over enthusiastic promotion of 'modest outcome effects' and the prioritisation of reducing demands on healthcare over addressing the needs of those living with a long-term health condition. Further commentary highlights issues of low reach [1, 36], high drop-outs and poor attendance [9, 37]. There has been limited research that explores the experiences of participation of participants and/or facilitators. Understanding these experiences will provide additional insight into the role of group-based programmes, how they work and their potential to support self-management. The aim of this paper is to investigate, through a systematic review of qualitative research, the experiences of participants and facilitators of group programmes for the self-management of long-term conditions. Our objective is to explore what is valued by facilitators and participants, and the similarities and differences between their experiences. The review informs a larger study aiming to better understand (1) how self-management support is interpreted and enacted; and (2) how self-management goals are negotiated between people with long-term conditions and their healthcare providers.5)

2. Methods

2.1 Search strategy

Seven electronic databases were searched by the lead author (SH): Scopus, Medline, PsychINFO, AMED, Cinahl, Sociological Abstracts and Embase. The search was limited to peer reviewed studies published in English during the period from January 2000 to February 2016, chosen to include the introduction of the CDSMP. Articles were identified using the keywords: self-management (or self-care*); group; and qualitative. These terms were used to capture the qualitative studies of group programmes that used or referred to the 'self-management' and/ or 'self-management support' concepts. Self-management was considered alongside self-care because, despite conceptual differences [15], the terms appear interchangeably in studies. The term 'qualitative' was used to identify articles exploring the experiences of group participation. A hand search (including reference lists) and February 2017 re-run of search terms was conducted.

2.2 Eligibility

Eligibility for inclusion of papers was based on 4 criteria. Studies were included if they: studied group programmes for self-management ; used qualitative methods; focused on the experiences of being a participant (both completers and non-completers) and/or a facilitator; and were for long-term conditions generically, diabetes, COPD or obesity. Including conditions with different characteristics was important to provide diverse self-management programmes. Further these three conditions were chosen for their increasing prevalence [38], and/or guidelines for management that refer to group-based programmes.

The search yield was initially screened by title and abstract (SH). Full texts of the retained studies were obtained and screened independently by two authors (SH, LS or SL) for eligibility. Any discrepancies were discussed until consensus was achieved.

Quality of articles was critically assessed independently by two researchers (SH and LS or SL) using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist [39]. A three tier ratings scale [40] was used to grade the studies as 'strong' (greater than two thirds 'yes' scores), 'moderate

(between one and two thirds 'yes' scores) or 'poor' (less than one third 'yes' scores). Studies of poor quality were excluded.

2.3 Analysis

Initially, following the Pound et al. (2005) [41] approach, studies were organised by publication date, country, participant characteristics, data collection methods, programme focus (condition), programme description, facilitator type and data source. Study findings, first order (respondent quotes) and second order (authors' interpretations) constructs, were grouped into facilitators or participants for separate coding. Analysis was conducted thematically following Thomas and Harden's (2008) [42] three step method for thematic synthesis. Step 1, initial coding was conducted line by line by SH. Step 2, descriptive themes were constructed and compared across the contextual groups of programme focus (condition), programme description and facilitator type. Step 3, analytical themes were developed which integrated and synthesised the themes from studies on group facilitators and group participants. Descriptive and analytical themes were refined through discussion with, and independent review by, LS and SL. Interpretation differences were resolved and consensus was reached through regular discussions (SH, LS and SL). Group discussions enabled critical reflection and challenging of assumptions brought to data interpretation and resolution of differences. The process of analysis is shown in Figure 1. Guiding this review was an interpretivist viewpoint from which we considered the individuals' (participants and facilitators) meanings of group programme participation.

| Text – Facilitator | Sub theme | Analytical theme |
|--|---|------------------------------|
| <i>I think open discussion is probably really good ... but you just have to have a tight control on bringing it back</i> | Facilitators' authority and challenges to authority | Tensions of group leadership |
| <i>The misinformation—sometimes we can get into a little tug</i> | | |
| <i>letting the group be the expert and then correcting people</i> | | |

Figure 1. Example of thematic synthesis steps

3. Results

After removal of duplicates (n=386) an initial yield of 2126 titles and abstracts were screened and 40 met the inclusion criteria. After full text review and quality appraisal ('poor' excluded n=3), 24 articles were included in the review. Figure 2. provides a PRISMA flow diagram of this process. An overview of the studies included in the review is in Table 1.

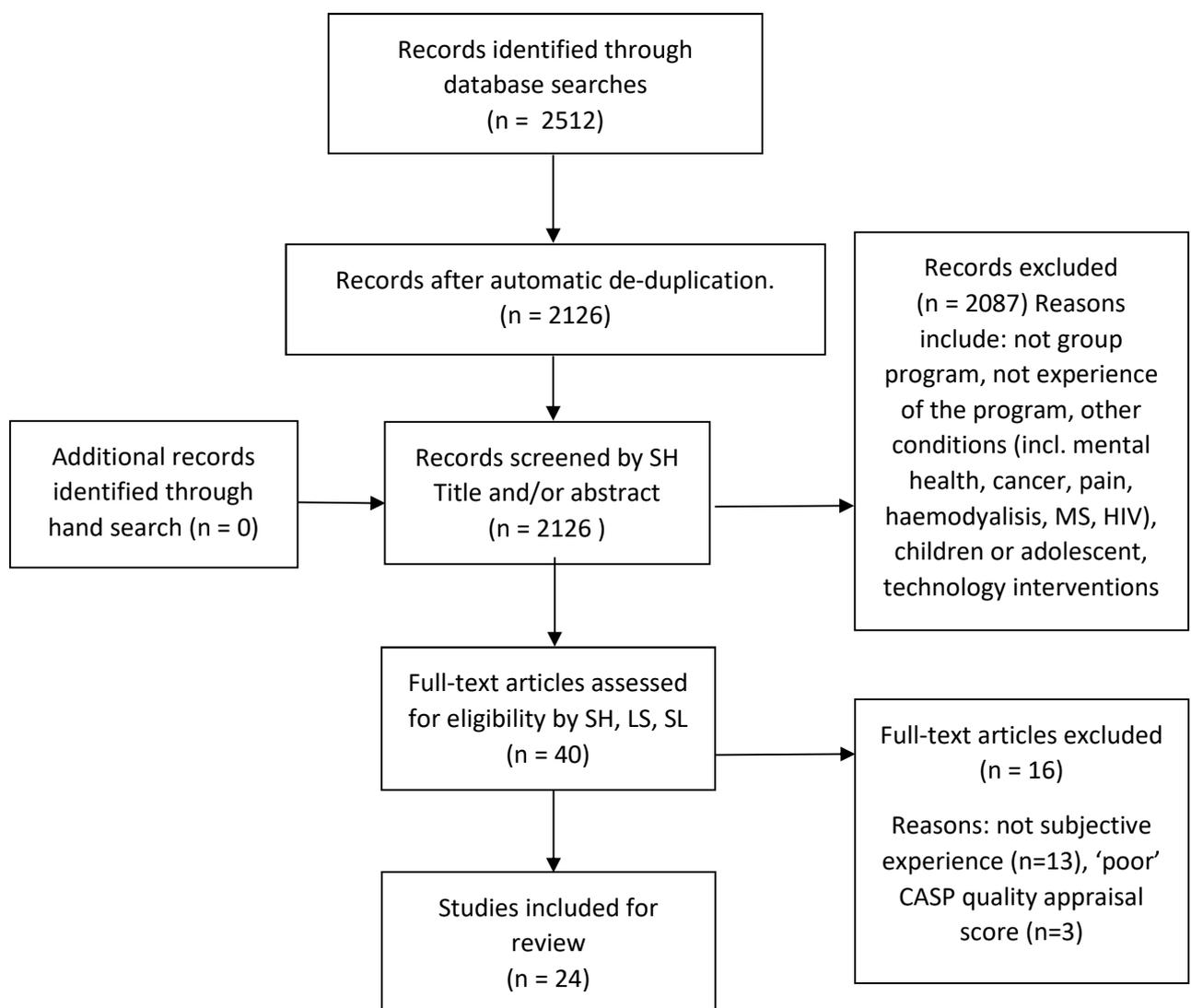


Figure 2. Diagram for selecting studies - PRISMA

[insert] Table 1. An overview of the studies included in the review

The 24 included studies were from the UK (n=5), the USA (n=5) Europe (n=6), Australia (n=4), Canada (n=2), South Africa (n=1) and Thailand (n=1). Group programmes were diverse in terms of: facilitator (HCPs (n=11), peer lay persons (i.e., a person with a long-term condition) (n=6), lay persons (i.e., a non-HCP) (n=5), co-led (i.e., a HCP and a lay person) (n=2)); condition focus (generic (n=11), diabetes (n=10), COPD (n=2), obesity n=1); and programme (self-management (n=13), education for self-management (n=5), lifestyle (n=2), group medical visit for self-management (GMV) (n=2), support (n=1), self-help (n=1)). Data collection methods included individual interviews (n=17), focus groups (n=9) and observations (n=3). Nine used more than one method. Study data was reported from group participants (n=12), group facilitators (n=5) or both (n=7).

Of the 19 studies with participant data, no studies included programme non-completers. All of the studies that were lay-, community health worker-, or co-led (n=13) noted that the facilitators received training prior to the programme. In contrast, only two HCP-led programmes mention programme-specific training [43, 44]. Seven studies were part of an intervention with an evaluation component [44-50]. A summary of the characteristics of included studies is presented in Table 2.

Table 2. An analysis of study characteristics

| Study characteristics | Number of studies |
|--|-------------------|
| Programme facilitator type | |
| HCP | 11 |
| Lay (peer) | 11 (6) |
| Co-led (HCP/Lay, HCP/peer) | 2 (1,1) |
| Programme focus (long-term condition) | |
| Generic | 11 |
| Diabetes | 10 |
| COPD | 2 |
| Obesity | 1 |
| Programme description | |
| CDSMP based | 9 |
| Education | 5 |
| Self-management | 4 |
| Support/ self-help or lifestyle | 4 |
| Group medical visit | 2 |
| Study participant data source | |
| Group participants | 12 |
| Group facilitators (3 HCP, 1 lay) | 5 |
| Both (Facilitators: 3 HCP ,3 lay, 1 both) | 7 |
| Data collection methods* | |

| | |
|----------------------------|----|
| Individual interview (SSI) | 18 |
| Focus group | 9 |

*some studies used multiple methods

Three main themes were identified: (i) The value of the group to participants; (ii) Tensions and challenges of group leadership; (iii) Dichotomised categorisation of participants and behaviours as positive or negative. Each theme will be discussed in turn.

3.1. *Value of the group to participants*

A prominent theme across the studies involving participants in group programmes was the value placed on being part of a group and interacting with others who shared similar condition-related experiences. The latter included both the social benefits of being *with* others living with a long-term condition, and the benefits of sharing knowledge and skills and working together with group members. Whilst studies emphasised the positive experiences of participating in a group programme, negative experiences were uncommon. Only two studies reported group participants perceiving little value from the group or affinity with group members [51, 52].

3.1.1 *Being with people like me*

The importance of being with people who shared similar experiences (and challenges) of living with a long-term condition was evident across both condition-specific (e.g. diabetes) and generic self-management programmes. The group participants reported feeling a sense of ‘common purpose’, ‘being in the same boat’ and ‘solidarity’ with other group members [47, 51, 53-55]. In some studies, participants said that their illness experience was ‘acknowledged’, ‘accepted’ and ‘validated’ by other group members [45, 50, 51, 55, 56]. They also noted feeling implicitly understood in the group [53]. This was unlike in other social groups and social settings, for example with family members and friends, where group participants sometimes reported concealing or minimising their condition because of shame, guilt or fear of being a ‘burden’ [45, 50, 51, 55, 56].

Group participants also said that being with similar others made them feel less alone, less isolated and less marginalised [45, 46, 50, 56] because the group fosters a sense of ‘belonging’, social inclusion and emotional support [43-48, 50, 51, 54, 57]. This was evident even in programmes with minimal group interaction, such as programmes mainly focused on exercise or education [48]. The group was described as a ‘safe’, ‘open’, ‘equal’ and ‘non-judgemental’ space where participants felt comfortable to share both positive and negative experiences and feelings [44-46, 49, 51, 53, 54, 58].

Participants described how the group environment provided everyone with the opportunity to ‘have a voice’, ‘tell your story’, ‘talk freely’ and ‘open up to others’ (both group participants and group facilitators) who were empathic, encouraging and viewed as ‘their equals’ [43, 44, 47, 49-51, 53, 55, 58]. Group participants, particularly those from ethnic minority populations, low socioeconomic backgrounds or rural areas, described feeling more comfortable and less intimidated asking questions in a group setting than in one-to-one interactions with a healthcare professional [43, 49, 58].

With a group you have a feeling of being part of many, whereas when I’m here with you or with my doctor, or one-on-one, quite often you’re intimidated by someone who knows more than you do Participant, Generic SM, Group medical visit (GMV) [58]

Group interactions were important to group participants and were emphasised more strongly than other aspects of group programmes (such as course content or skills acquired). This was most in evidence in studies which explicitly sought participants’ views about programme structure and process, over participant experience [59]. However, in a number of studies, some participants expressed disappointment that their programme provided limited opportunities to interact with other participants and were critical of the rigidity of programmes or programme facilitators which they felt constrained group interactions which were deferred for tea breaks and before and after class [43, 50, 56].

Sometimes it hurts me a little bit to see that some people are directly cut off if they want to add something or that they are put off until the break. Participant, Generic self-management [50].

Group settings also provided opportunities for participants to compare their own situations to those of others. Group participants in a number of studies reported this to be beneficial [44, 48, 51, 53, 55, 57]. ‘Downward comparisons’, where participants compared themselves with ‘worse off’ group members, made individuals feel more positive, ‘lucky’, or motivated them to manage their condition to prevent worsening symptoms:

...I did think “Well you’re not as bad as what other people . . .” And I looked at some other diabetics and they were in quite a bad way, you know. Oh God, I’m quite lucky really ...Yeah it was good. It did make me feel good . . . Participant, Generic SM [51]

Upward comparisons, although less common, were reported as providing reassurance, inspiration and motivation for some participants [55], for example, by seeing more experienced others ‘doing well’ [50]. In contrast, in one study, observing others ‘doing well’ could be distressing or threatening for some group participants [51].

3.1.2 Working together and learning from each other

Participants articulated valuing knowledge, ideas and skills gained from others through working and problem solving together [43-47, 50, 51, 54, 55, 57, 60]. Sharing experiential knowledge and strategies (including difficulties, challenges and emotions) helped group participants to improve their understandings of their condition [47, 56] and adopt new strategies for self-management [44, 45, 47, 55-57]. In some studies, participants reported that other group members were able to translate (often) complex medical information from the programme facilitator into a form which ‘made sense’ [45, 56]. In this way, group members could help bridge gaps in understanding of information between group facilitators and group participants.

Learning from others increased participants' sense of control, self-efficacy, self-confidence and motivation to manage their condition [44, 45, 47, 48, 53-58] and reduced feelings of uncertainty and insecurity [46, 48, 50, 55]. In addition, feeling that they were helping other group members increased participants own sense of self-worth [51].

In studies where goal setting constituted a programme component, participants reported how sharing their goals with the group made them feel more committed to achieving them [50, 55, 57, 61] and accountable to the group if goals were not achieved. Yet they still felt encouraged and motivated by working with others, regardless of whether they were successful in making changes or not [44, 50, 55]

But once you've committed yourself and you've told somebody else. To go back and say, well I didn't do it, you feel guilty. To actually commit yourself to doing something and doing it makes you feel quite proud of yourself. Participant, Generic SM [55]

3.1.3 Negative group experience

Studies reporting on group participants' experiences were overwhelmingly positive. Negative experiences were uncommon, or when referred to were often not discussed in depth. As an example, in one study [53], reporting of findings was skewed towards eight (of 11) participants who reported participating in a group programme as beneficial. The three participants who did not report benefits were not quoted as the authors interpreted their experiences as 'contradictory'. However, they went on to state that through the process of being interviewed, these participants had come to realise the benefits of the programme:

⇒patients reported various new initiatives that made the researchers aware of their increased self-care abilities. Strikingly, the patients were not always able to identify these positive behaviour changes themselves. COPD, Education

Authors thus concluded that: ‘an effect of patient education may be achieved even when all participants do not recognise it.’ Yet, this makes assumptions about participants’ health behaviours being an outcome of participation in a programme, and disregards participants’ own perspectives.

In contrast to what was valued by the group participants were differing values and expectations stated by the facilitators.

3.2 Tensions of group leadership: expectations and challenges

The ways in which facilitators perceived their role varied which given the diverse nature of programmes is unsurprising. However, this was not consistent within and across the studies. A commonality in the responses of group facilitators was feeling obligated to monitor group discussions, correct misinformation and control participants they saw as negative, difficult or disengaged. Facilitators rarely talked about the intended health outcomes of group programmes, and described group participant behaviour change as being an unlikely occurrence.

3.2.1 Facilitators’ goals and expectations

Group facilitators in a number of programmes [62-65] (generic SM (lay and HCP); diabetes support (HCP)) stated their main focus was to provide support to group participants, and help them to achieve a good ‘quality of life’ [62]. This included efforts to ‘normalise’ the lived experience of having a condition [62, 64, 65]. A few facilitators noted that just being in a group with similar others was effective at achieving this.

The group dynamic is really effective for patients normalising how they feel. HCP facilitator, Generic Self-management [65]

In contrast, some facilitators from a self-management Group Medical Visit (GMV) programme said they focused on developing healthy behaviour ‘norms’ in the group to try to encourage behaviour change [58]. For example, one group facilitator encouraged participants to be accountable to each other:

when you're in a group ... you have to face up to the other people... HCP facilitator, Generic SM GMV [58]

HCP facilitators from diverse programme types (generic SM, diabetes education, GMV), said that their main focus was to provide education [43, 49, 58, 65] as they valued evidence based knowledge and getting participants to “understand what they needed to understand” [58]. Some facilitators said they presented the information and then ‘allowed’ discussions within the topics [65].

HCP Facilitators from a self-management programme said they focused on making group sessions enjoyable so that participants would continue to attend [65]. Lay facilitators said facilitating was a significant personal challenge that helped them build self-confidence [63, 66].

I think it [facilitating] increases your confidence ... and it helps to make you feel normal again ... It's very, very rewarding. Lay facilitator, Generic SM [63]

3.2.2 Facilitators' authority and challenges to authority

Facilitators' narratives revealed tensions around retaining and giving over authority within the group context. On the one hand they described a belief in holding back their advice and trying not to lecture so as to promote group problem solving, interactions between participants and an ‘even playing field’ [58, 62, 65] but, on the other hand facilitators saw themselves as having a ‘supervisory’ role in the group interactions, needing to ‘control’, and monitor the discussions so they could correct ‘misinformation’ if and when it occurred.

I think open discussion is probably really good for improving the group dynamic, but you just have to have a tight control on bringing it back around when you feel there's been enough. HCP facilitator, Generic SM [65]

Many facilitators described the challenge of managing behaviours or actions they viewed as ‘disruptive’ to the group [49, 56, 62, 65]. This was particularly evident among HCP facilitators and they described strategies, such as stipulating group rules [49, 62, 64, 65], whereas lay facilitators did

not [56]. For example, in one study involving HCP facilitators, group facilitators noted needing strategies to 'deal with a negative presence' as a challenge of facilitating group dynamics [62]. In a study of HCP facilitators working with peer facilitators, HCPs commented that some peer facilitators could also bring 'the group down with their negativity' [64]. Lay facilitators relayed the challenges they experienced in maintaining control of sessions and in keeping participants to pre-determined session structures [52, 63].

Some experienced difficulties recruiting participants and others noted poor attendance and drop-outs during the programme [49, 56, 61, 63, 65]. The characterisation of 'negative' participants and the contrasting predominant characterisation of compliant 'good' participants are explored further in the following theme.

3.3 Dichotomised categorisation of participants and behaviours as positive or negative

Facilitators (HCP and lay) used positive language when discussing particular group members and group behaviours and, in contrast, negatively portrayed group members and group behaviours they saw as deviant and disruptive. Facilitators noted that 'good' participants were those who displayed positive behaviours that aligned with their own values, beliefs and knowledge.

Facilitators' positive descriptions of participants included the achievement of change such as moving their 'illness forward', displaying belief in themselves or simply trying. They also described preferred participants as those capable of 'enjoying themselves', having 'a good time', remaining focused, participating or regularly attending.

It's a tremendous buzz when you see someone ... actually believes in themselves and believes that they have got some control over their destiny. Lay facilitator, Generic SM [63]

Lay and peer facilitators also noted feeling an imperative to be 'good' and to role model healthy behaviours [60, 63, 64, 66].

In contrast, 'problem participants' were described in some studies as a 'small minority' whose negativity threatened other group members' self-efficacy and created 'problems' for facilitators [56]. No data from group participants' interviews were used as evidence to support the assertions that group participants perceived other group members as disruptive or negative. Indeed, in one study, a 'mismatch' was noted between group facilitators who complained about 'late comers' and group participants who did not raise this as a concern [49]. In another generic programme, participants emphasised the value of encouraging and supporting struggling group members [57].

Facilitators (both HCP and lay) drew on negative examples of participants' characteristics or behaviours such as being 'strongly opinionated', 'difficult', 'non-compliant' or 'dominant' [49, 56, 65]. What they described as 'non-compliance' was scorned and described as a problem of certain people with chronic conditions who were 'set in their ways', did not 'care' about their health, lacked 'drive' willpower and discipline or were 'lazy'.

But most of our patients don't have that drive and they don't care, they care about food and alcohol or whether it is something else and not their health. HCP facilitator, Diabetes education [49]

Authors of many studies [44-46, 50, 54, 57, 59] drew attention to positive experiences and outcomes of group participants collectively and this was particularly evident in diabetes specific programmes. For example, these authors highlighted participants' gains in 'understanding', knowledge and 'learning', and motivation. Authors' interpretations of individual experiences that were neutral were absent from these studies, and negative experiences were downplayed. An example of authors' positive language can be seen in the following quote:

Program improved ability to manage diabetes by providing new knowledge, a broader context, improved understanding and motivation to manage better. Diabetes SM [45]

These judgements about 'good' and 'bad' characteristics were used in the studies to separate and contrast the small number of unmotivated participants from the 'motivated' majority.

Most felt motivated to attend because of desire to get healthy and previous positive experiences. ... Others were less interested and therefore lacked motivation. Diabetes GMV [54]

4 Discussion and conclusion

4.1 Discussion

This review provides insights about the experiences of participants and facilitators of group self-management programmes for people with long-term conditions. This is the first review to our knowledge to explore the qualitative data on self-management group programmes using the perspective of both group participants and facilitators. There appears to be a disconnect in what is valued from many group-based self-management programmes between group participants and the group facilitators. Across the studies, group participants valued the opportunity for interaction with other people who shared similar experiences to themselves, and the emotional and social benefits that they gained through these interactions, yet the importance of this to participants was only superficially recognised by facilitators and either not included or hindered by the programmes' structure. Facilitators' often narrow interpretations of self-management around education and conformity to lifestyle changes coexisted with low expectations of participants' abilities to achieve these changes. Counterintuitively, and in light of the intervention based research that predominates, biomedical outcomes and behaviour change were rarely discussed, by either group participants or group facilitators.

Our findings showing that people with a long-term condition from group programmes valued the support they received from those with similar experience, provides support for the theoretical work of Thoits et al. [67-69] who have theorised that people undergoing stressors such as coping with a long-term condition perceive the support from others with similar experience as being more

empathic and less judgemental and therefore uniquely valuable to them. Other studies have noted that formal group programmes may provide an important conduit for people with long-term conditions to connect and rebuild diminished support networks [70, 71]. For example, in a recent study group participants increased their social support network and by turning to each other reduced their utilisation of health services [70]. The participants' descriptions of what they valued from participation in the group, including being with similar others, comparing, sharing, learning from each other and working together to solve problems, align with reviews into peer support interventions [72], current understandings on the needs of people with long-term conditions and theories of social learning [73, 74]. In contrast, facilitators' descriptions were varied and unclear with regards to how and why they delivered programmes in the manner they did and, what their expectations were for the participants. Importantly, what participants valued also aligns with key components of self-management programmes such as being collaborative and focused on problem solving. A recent qualitative study [75] found two reasons for self-management group attendance - participants had practical problems and felt insecure, and through participation they hoped to gain contact with similar others and to access contradictory information.

This review highlights that group programmes and facilitators, by focusing on medical aspects of self-management, may be constraining opportunities to provide support, reassurance, the building of self-confidence and the maximising of agency that is at the core of self-management and, further, appears highly valued by the participants. Further, facilitators appear to lack the theoretical understanding, training and confidence to be able to support participants beyond a medical paradigm. Despite the programmes' constraints and the negative experiences reported by some participants, individual and collective benefits appear to have been created in the groups. However, the studies in this review have not provided a rigorous enough exploration for our synthesis to explore how this occurs. The experiential value attributed to participating in a group suggests that the notion of co-production in the context of self-management support aligns with what is valued by participants of group programmes and extends beyond enacting a more equal and reciprocal

relationship between professionals and people with long-term conditions. Rather it requires more of a focus on co-production in terms of connecting to a broader set of ties with others which can provide meaningful relationships which form the bases of reciprocity and are in turn mediators of relevant resources and activities for self-management in community and neighbourhood environments. This points to future research extending beyond professional-patient interactions in closed group programme settings to include a broader focus on the role of others within the personal networks of those with long-term conditions, in providing support or becoming more effective agents of change [76].

4.1.1 Structural limitations

A key finding of this review was that many of the included studies, according to the CASP qualitative checklist, were of moderate quality (n=9) and that few high quality qualitative studies were found. Further, many studies (n=7) were nested within RCT and evaluation studies suggesting that they were focused on understanding outcomes and process rather than being open to exploring the full diversity of experiences. This suggests that further data is needed from rigorous, standalone qualitative studies to gain a deeper insight into the experience of participation in self-management programmes. This is a clear limitation of the reviewed studies. Our review sought studies of group programmes (generic, COPD, diabetes type 2 and obesity) that self-describe a 'self-management' objective. We also note as a limitation, inconsistencies in interpretations of self-management by programme designers and facilitators. The experience of facilitators and participants of programmes in our review may not be representative of the experience in other self-management programmes. Finally, all participants in the studies were course completers and hence the views or experiences of participants who dropped out are absent. While this may be difficult to address, more research is needed to ascertain the needs and experiences of these participants. Bossy et al. [77], in a recent study looked at attendees and non-attendees of group diabetes programmes and found a divergence between those wanting to be with similar others and those who formed an identity

around coping on their own. This is an important new line of inquiry that requires further exploration.

4.2 Conclusion

Our qualitative review has provided relevant experiential findings from participants and facilitators of group programmes supporting self-management of long-term conditions. It has shown that shared learning and social support outcomes of group programmes, highly valued by participants, are being sidelined by a collective presumption that evidence based medical education and compliance is the core purpose of self-management. Our findings suggest that this mismatch of purpose between participants and facilitators of group programmes may be reducing the opportunities for programmes to contribute to patient-valued, collective outcomes based on common experience and connectivity to others. It is unclear what the ramifications of these group programmes are for the abilities of participants to propose and pursue goals that can meaningfully guide their self-management. We note that further rigorous studies are needed in this area and that the value of participation and connectivity with others is conducive to a broader social network approach to self-management support that extends beyond professionally facilitated programmes.

4.3 Practice implications

This review supports a significant broadening of the scope of group based programmes to de-privilege self-management medical education and compliance in favour of broader self-management ideas that include shared learning, social (communal) support and the development of agency. Therefore, our findings are relevant to those involved in the design and delivery of group programmes and to those concerned with addressing the societal and individual burden of long-term conditions.

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Table 1. An overview of the studies included in the review

| | Programme/ leader | Aims | Method | Sample | Findings | CASP score |
|---------------------------------------|--|--|---|--|---|-------------------|
| Monninkhof et al. 2004 Netherlands | COPD SM/ HCP (various) | To assess how patients perceive the effects of intervention on quality of life. | Semi-structured interviews; grounded theory analysis | 20 participants | Fitness programme most valued Increase self-confidence, coping important Frequency follow-up increased feeling of safety | Strong |
| Barlow et al. 2005 UK | Generic SM (CDSMC)/ Lay (peer) | To examine perspectives on course delivery and impact on their own SM. | Telephone interviews; content analysis to identify themes | 11 lay facilitators (with chronic conditions) | Enjoyable and valuable experience Tension betw. disease specific and generic approach Being valued and adding value were key benefits | Strong |
| Barlow et al. 2005a UK | Generic SM (CDSMC)/ Lay (peer) | To understand experiences of CDSMC and use of SM. | Telephone interviews, content analysis to identify themes | 9 participants | Shared experience in reassuring environment Goal setting critical in making changes Provided confidence to select appropriate SM tech. | Strong |
| Two Feathers et al. 2007 USA | Diabetes culturally tailored lifestyle/ Lay | To describe the development, implementation, and process evaluation of intervention. | Focus groups (facilitator and participant) and obs.; content analysis. | 32 participants (AA&L), 10 facilitators (AA&L) | Information and activities useful, culturally relevant Convenient community location Appreciated social support from other participants | Moderate |
| Wilson et al. 2007 UK | Generic SM (EPP)/ Lay (peer) | To explore whether the EPP reinforces medical paradigm or enables empowerment. | Focus groups (part.), semi-structured interviews (tutors & part.), obs.; grounded theory. | 66 participants, 2 tutors | Expert patient characteristics revealed Paradoxical reinforce medical paradigm and supporting and acknowledging lived experience | Strong |
| Adolfsson et al. 2008 Sweden | Diabetes education/ HCP physician, nurse) | To explore experiences of empowerment programme or individual counselling. | Semi-structured interviews; content analysis | 28 participants | Relationships horizontal, trusting, mutual Learning is participatory Achieved insight diabetes serious, can be influenced | Moderate |
| Catalano et al. 2009 Australia | Generic SM (CDSMC)/ HCP (various) and lay (peer) | To perceptions of working together to deliver SM. | Semi-structured telephone interviews; systematic coding process analysis | 17 peer and 17 HCP facilitators | The value of working together HCPs not always understanding of the benefits of Ps Ps observed status disparities and lack of ownership | Strong |
| Heisler et al 2008 USA | Diabetes SM / Lay (CHW) | To explore reasons for intervention on outcomes. | Semi-structured interviews; thematic analysis. | 40 participants (AA&L) | Improved diabetes SM ability Clear and detailed information, education, training Non-judgemental assistance; social and peer support | Moderate |

| | | | | | | |
|---|--|---|--|--|--|----------|
| Rogers et al. 2009 UK | Generic SM (EPP)/ Lay (peer) | To examine the process of social comparison. | Semi-structured interviews; thematic analysis | 31 participants | Social comparison underlies group dynamics Positive comparisons = beneficial self-evaluation, allow social, morally worthy self-presentation | Strong |
| Castillo et al. 2010 USA | Diabetes education/ Lay (CHW) | To extend and explain findings from evaluation. | Focus groups; thematic analysis | 15 participants (Hispanic/ Latino) | Increase in perceived competence in self-care CHWs positive influence on program compliance | Moderate |
| Stone and Packer 2010 Australia | Generic SM (CDSMP)/ HCP and Lay (peer) | To report implementation processes and outcomes. | Semi-structured interviews; thematic analysis. | 12 facilitators (HCP) or managers, 14 participants (rural) | Leaders believed participants benefited Participants valued information, sharing, co-led mix Want more time for goals | Moderate |
| Sukwatjane et al. 2011 Thailand | Diabetes self-help/ HCP (nurse participant investigator) | To explore perspectives on their self-care ability and quality of life. | Group discussions and observations; content analysis. | 20 participants (rural Thai) | Cultural knowledge gained from shared experiences Successes from members' recommendations Social support, empowerment and self-efficacy | Strong |
| Mousing and Lomborg 2012 Denmark | COPD education/ HCP (various) | To explore how influences self-care. | Semi-structured/ group interviews; thematic analysis | 11 participants | Increased condition knowledge, tools Social aspects motivated them to utilise new habits HCPs focussed attention on new skills | Strong |
| Aoun et al. 2013 Australia | Obesity Lifestyle modification/ Lay | To explore experiences with programme and their perceived role. | Teleconferences or written feedback; thematic analysis | 20 facilitators (lay) | Enjoyed role, felt responsible, role modelled Gave a sense of purpose, empowerment, knowledge Difficulty motivating participants to change | Strong |
| Costello 2013 USA | Diabetes support/ HCP (nurse educator) | To explore roles and strategies. | In-depth interviews and group interview; thematic analysis | 6 facilitators (HCP) | Roles: shared authority, QOL focus, not perfectionism Strategies: connecting, exchanging, dynamics, problem solving | Moderate |
| Lavoie et al. 2013 Canada | GMV (generic SM) / HCP (various) | To identify format and process elements and explain improved health outcomes. | Semi-structured interviews; thematic analysis | 29 participants (rural) and 34 facilitators (HCP) | Role to assisting group define the norms of self-care Increased trust, knowledge, better self-manag. Increased satisfaction for patients and providers | Strong |
| Van Der Does and Mash 2013 South Africa | Diabetes education/ HCP (various) | To evaluate programme | Individual interviews HCPs; focus groups patients (6); framework analysis. | 84 participants (low socio-economic); 11 facilitators | Comprehensive education appreciated Group process deemed supportive HCPs doubt effect of education in general | Moderate |

| | | | | | | |
|-------------------------------------|---|--|--|---|--|----------|
| Harvey and Janke 2014 USA | Generic SM (CDSMC)/ Lay | To understand SM strategies used, and how course promoted change. | Focus groups; phenomenological/ consensual analysis | 34 participants (rural) | Identify with peers making positive health changes Confident in future change through empowerment Strategies employed included goal setting | Moderate |
| Thompson et al. 2014 Canada | Diabetes GMV/ HCP (nurse and dietitian) | To generate insights for development. | Semi-structured interviews; content analysis | 9 participants (low socioeconomic males) | Good fac. = credible, understand patient experience Group members role to support change process | Strong |
| Voigt et al. 2014 Denmark | Diabetes education/ HCP (various) | To explore the utility of action research. | Action research: existing: HCPs & patients, obs., participant interviews; new: pat. interview & obs.; thematic analysis. | 8 facilitators (HCP diabetes educators), 7 participants | Participatory learning compared with regular HCP Practical and social learning valued | Strong |
| Haslbeck et al. 2015 Switzerland | Generic SM (CDSMP)/ Lay (peer) | To describe adaptation and implementation process, report evaluation. | Focus groups and semi-structured interviews; thematic analysis | 56 participants | Receptive to peer led approach, found methods useful Structure did not address all needs or expectations Positive impacts on coping and self-care | Moderate |
| Odgers-Jewell et al. 2015 Australia | Generic SM education/ HCP (various) | To explore fac. Perceptions of the attributes for effectiveness. | Semi-structured interviews; thematic content analysis | 14 facilitators | Fac. unaware of theory, few had group training Programme effectiveness from group interactions, non-didactic delivery, multi-disciplinary, practical activities | Strong |
| Sidhu et al. 2015 UK | Generic s SM (CDSMP culturally tailored)/ Lay | To evaluate and describe experiences of lay educators, evaluate whether delivered as intended. | Semi-structured interviews & group obs.; thematic analysis. | 6 facilitators, 20 participants (non-English speaking South Asian), 14 obs. | Lay educators felt part of local community Challenged addressing beliefs, changing lifestyles Value in cultural appropriateness and group-based | Strong |
| Herre et al. 2016 Norway | Diabetes SM/ HCP (various) | To understand experience of participation and how influences SM. | Focus group; mechanical and interpretative analysis | 22 participants | Increased theoretical and practical understanding Awareness of need to take diabetes seriously Also learned from each other | Strong |

Appendix 1. Description of current self-management programmes

| | CDSMP | Diabetes | COPD | Obesity |
|---------------------------|--|--|--|---|
| Organisation | Stanford University http://patienteducation.stanford.edu/programs/cdsmp.html | American Diabetes Association (ADA) http://professional.diabetes.org/ | Global Initiative for Chronic Obstructive Lung Disease (GOLD) http://goldcopd.org/gold-2017-global-strategy-diagnosis-management-prevention-copd/ | World Obesity Federation https://www.worldobesity.org/ |
| Guideline or standard | N/A | National Standards for Diabetes Self-Management Education and Support | Global Strategy for the diagnosis, management, and prevention of COPD | No guidelines or standards for self-management. |
| Key SM programme elements | Exercise, nutrition and medications. Techniques for individual to deal with associated physical and psychosocial problems. Communication. | Exercise, nutrition and medications. Disease monitoring and decision making, acute and chronic complications. Strategies for individual to address psychosocial issues and behaviour change. | Notes evidence insufficient for specific recommendation. Structured and personalised. Goal to motivate, engage and support to positive behaviour change. Develop skills. | N/A |