How do facilitators of group programmes for long-term conditions conceptualise self-management support?

Authors: Stephen Hughes¹, Sophie Lewis², Karen Willis³, Anne Rogers⁴, Sally Wyke⁵, Lorraine Smith¹

The University of Sydney School of Pharmacy, Faculty of Medicine and Health, Building A15, The University of Sydney, NSW, Australia, 2006.

Author addresses:

¹The University of Sydney School of Pharmacy, Faculty of Medicine and Health, Building A15, The University of Sydney, NSW, Australia, 2006.

²Faculty of Arts and Social Sciences, University of New South Wales, Sydney, New South Wales, Australia, 2052.

³Allied Health Research, Melbourne Health, La Trobe University, Royal Melbourne Hospital, Parkville, Victoria, Australia, 3052.

⁴Faculty of Health Sciences, University of Southampton, Highfield, Southampton, SO17 1BJ, United Kingdom.

⁵Institute for Health and Wellbeing, College of Social Sciences, Room 204 25-28 Bute Gardens, G12 8RS, United Kingdom.

Corresponding author:

Stephen Hughes, The University of Sydney School of Pharmacy, Faculty of Medicine and Health, Building A15, The University of Sydney, NSW, Australia, 2006.

Telephone: +61 2 9036 7079, stephen.hughes@sydney.edu.au, Fax: +61 2 9351 4391
Abstract

Objectives

Increasing self-management skills in people with long-term conditions (LTCs) is widely advocated in policies and guidelines. Group programmes are a common format, yet how self-management support (SMS) objectives are enacted in their delivery is poorly understood. Our aim is to explore the perspectives of group programme facilitators.

Methods

We undertook thematic analysis of transcribed data from in-depth semi-structured interviews with health practitioner facilitators (n=13) from six diverse SMS group programmes (of obesity, diabetes and COPD).

Results

Facilitators viewed group programmes as responses to health system pressures e.g. high patient demand. They focused on providing in-depth education and instruction on physical health, risks and lifestyle behaviour change, and emphasised self-responsibility for behaviour change whilst minimising goal setting and support amongst group participants. There were tensions between facilitators’ practitioner identity and group leader role.

Discussion

Group SMS programmes, may not be realising the broader aspirations advocated in LTC policy to support medical, emotional and social aspects of LTCs by minimising shared learning, problem solving, building of self-efficacy and goal setting. This suggests a disconnect at implementation. Increasing understandings of theoretical and practical SMS in group programmes across both implementation and HCP training will further the professional skills in this format.
Key words: self-management, group programme, long-term condition, qualitative

Introduction

The increasing prevalence of long-term conditions is a challenge for healthcare providers and systems in terms of healthcare costs and professional resourcing as well as in how to support people to live well with a long-term condition. A myriad of health policies, frameworks, strategies and standards for the management of long-term conditions have emerged in Organisation for Economic Co-operation and Development (OECD) countries, which suggest ways that health practitioners should support and deliver care to patients who are living with a long-term condition. These documents articulate the need for practitioners to help facilitate self-management by fostering skills, knowledge and behaviours that enable their patients with long-term conditions to take a more active role in their own care. In Australia, for example, the 2017 National Chronic Condition Strategic framework advises health providers to support individuals to develop self-management ‘skills and resources’ in the priority area of ‘active engagement’ (Page 24). Tested theoretical models and programmes for self-management support emphasise the importance of a specially trained workforce to facilitate patients’ problem solving and goal setting skills, and to help patients build self-efficacy, which responds to the medical, emotional and social aspects of managing a long-term condition.

Group-based self-management programmes are a common format used for providing self-management support. They also provide opportunities for shared learning and peer support, which is central to programmes based on the lay-led Stanford Chronic Disease Self-management Program (CDSMP). Empirical evidence suggests that support from experientially similar others, as found in groups, benefits physical and psychological wellbeing and, a recent qualitative review of group SMS programmes showed participants valued being with similar others and gained confidence from the experience. HCP-led group programmes are a common format and are promoted by condition specific guidelines. The extent to which objectives of self-management...
support articulated in policy and research/theory, and the benefits of support from similar others, are translated into the delivery of HCP-led group programmes is still not well understood.

Overwhelmingly, research evaluating group programmes has focused on changes in biomedical indices and outcomes such as weight, lung function, blood glucose levels and treatment adherence. There remains limited understanding of how group programmes are envisaged and developed, and the extent to which the broad range of factors thought to comprise self-management support inform these processes. The need for greater understanding of the ‘breadth of self-management’ in this format has been previously reported. Further, little is known about whether group programmes seek to respond to the experiences, needs and expectations of the individuals who participate in group programmes. Those studies reporting on facilitators’ views have tended to focus on their evaluation of the programme rather than how they conceptualise their role and their experiences of being a facilitator. In particular, the perspective of group facilitators has rarely been studied, yet it is the facilitator who is vital to the enablement of self-management support in this format.

Therefore, in this study we aim to explore how group facilitators’ conceptualise self-management support in a group programme, their experiences of facilitating, their perception of their role and the challenges they identify.

Methods
Data from interviews with healthcare practitioners who are facilitators of group self-management programmes in New South Wales, Australia were used to investigate their experiences and perceptions. The facilitator interview data used for this study are drawn from a larger qualitative study about the role of goal-setting in chronic condition self-management that also gathered observation and participant interview data. A qualitative approach was taken to allow an in-depth exploration of the experiences and perspectives of healthcare practitioners engaged in group self-
management support. We received ethics approval from Sydney Local Health District (Protocol no: X15-0214) and The University of Sydney (Project no: 2016/898) human research ethics committees.

Sample and recruitment

We followed the approach of recent research into group self-management support that considered all LTC group programmes as self-management support if their aim is to support patients’ health-related activities. We limited to HCP led programmes for people with one of three chronic conditions (chronic obstructive pulmonary disease (COPD), type 2 diabetes, or obesity) chosen for their high prevalence and management guidelines promoting self-management in a group format. Using the research team’s networks and web searches we made contact via email and/or telephone with personnel from group programmes, invited participation and provided a study information sheet. Six programmes were selected across a range of locations (metropolitan/regional) and settings (e.g. hospital/community based). An overview of each of these programmes is included in Table 1. The facilitators of the group programmes were provided an information sheet about the study and invited to participate in the interviews. Study participants were informed that the lead researcher, a PhD candidate and healthcare practitioner with an interest in LTC management, was collecting interview data for a project on self-management and goal setting. No facilitators refused to participate.

Table 1. Overview of programme characteristics

<table>
<thead>
<tr>
<th>Programme description (development; guidelines/ theory used)</th>
<th>Site</th>
<th>Facilitators; training</th>
<th>Outcomes measured</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes education (external programme; adult learning theories)</td>
<td>Large metropolitan hospital outpatient</td>
<td>Dietitian (n=1); 2 hours external</td>
<td>Weight</td>
</tr>
<tr>
<td>Diabetes education (developed by facilitators; no theory)</td>
<td>Suburban general practice</td>
<td>Dietitian (n=1) and EP (n=1); no training</td>
<td>Weight, BP, HbA1c, BMI</td>
</tr>
</tbody>
</table>
Obesity education, (developed by facilitators; no theory) Large metropolitan hospital outpatient Physiotherapist (n=1), nurse (n=1), psychologist (n=1 dietitian (not interviewed); no training

Obesity lifestyle education (external programme; no theory) Rural, community hall / hospital meeting room Dietitian (n=2) and EP (n=1); facilitator manual, online modules with assessment

COPD rehabilitation (developed by facilitators; national guidelines) Large metropolitan hospital outpatient gym Physiotherapist (n=2); internal training and supervision

COPD rehabilitation (developed externally within local health district; national guidelines) Small metropolitan hospital outpatient gym Physiotherapist (n=2); external training and supervision

Weight, waist, hip, BMI

Weight, BP, exercise capabilities

Weight, height, lung function, respiratory symptoms, exercise capabilities, QOL, depression surveys

Weight, height, lung function, respiratory symptoms, exercise capabilities, QOL, depression surveys

Key: EP (Exercise physiologist), BP (blood pressure), BMI (body mass index), COPD (chronic obstructive pulmonary disease), QOL (quality of life)

Data collection

In-depth, semi-structured interviews were conducted by the first author between December, 2015 and April, 2017. Interviews were conducted face-to-face at the site or by telephone, were between 60-90 minutes and were audio-recorded with participants’ consent. An interview schedule was developed based on a review of the literature to guide the interviews and included questions about how their programme was designed, what the purpose of their programme was, their role in the delivery of the programme and their perceptions of group participants (table 2). Following each interview, detailed field notes were taken to initiate reflection and understanding.

Table 2. Semi-structured interview question schedule

<table>
<thead>
<tr>
<th>Theme</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working with LTCs</td>
<td>How did you come to be working in group programmes?</td>
</tr>
<tr>
<td></td>
<td>How would you describe your role?</td>
</tr>
<tr>
<td></td>
<td>Did you receive any training before you started this role?</td>
</tr>
<tr>
<td></td>
<td>What did that involve?</td>
</tr>
</tbody>
</table>
The perceived programme purpose
What do you focus on in your programme?
What do you see as the main purpose of your programme?
What do you want people to get out of the programme?
What do you think the participants want to get out of this programme?

The group
What do you believe are the benefits/disadvantages of healthcare in a group?
What interactions do you see occurring between the members of your groups?

The programme materials
In what ways do you use them?
How were they developed?
What are the theoretical/research principles (if any) that underpin the programme materials?

Goal setting
Do you think goal setting is important? Why? Why not?
Can you give me an example of how you incorporate goal setting into the programme?

Data analysis
Qualitative data software (nVivo 11) was used to manage and organise the data. Data was analysed inductively and thematically. A constant comparative method was used. First, all interview transcripts were read by SH, LS and SL. Emerging themes and concepts were noted and from these discussions a coding framework was developed where text was coded into categories and subcategories. Analysis and comparison across and within categories were conducted to develop final themes (SH, LS and SL). Three of the authors met frequently during the analysis process to compare and/or challenge individual interpretations, ensuring that analysis was conducted rigorously.

Results
Thirteen facilitators from six group programmes were interviewed and comprised five professions: physiotherapist, dietitian, exercise physiologist, nurse and psychologist. Facilitators were evenly distributed across age decades (20 – 59yo) and were predominantly female (female n=10, male n=3).
In the following sections we describe four main themes which emerged from analysis. 1) Facilitators recognised that contextual factors contributed to their programme’s existence and design. 2) Facilitators perceived the key purpose of their programmes was to provide health education and instruction to participants about the health risks of their condition, and the health benefits of behaviour change. 3) Facilitators’ views on their identities and roles illuminated tensions between ‘care provider’ and self-management ‘enabler’. 4) Facilitators placed an emphasis on participant self-responsibility for behaviour change while minimising the importance of self-management elements such as goal setting or support from the group and its members.

1) Programmes were responses to, and influenced/ limited by, system constraints

All facilitators talked about how their group programme was designed and developed as a response to health services under pressure from factors such as high patient demand for services, long waiting lists, high number of referrals, stretched resources and/or over-worked practitioners. They discussed working within, and being influenced out of necessity, by these contextual factors.

*We had too many patients on a waiting list...about 150 or more. ...the group programme was the way to...disperse the same information to a lot of people at the one time. (Facilitator 4)*

Some facilitators said that the availability of government funding to run group programmes for self-management was the impetus for their development. They saw group programmes as an opportunity to expand businesses, gain new clients and gain recognition amongst other practitioners.

*It allows us to open up individual sessions after the group sessions, you’ve got that relationship with the patient. (Facilitator 13)*

Facilitators also reported that to meet the external reporting requirements of management and funders, and for reporting back to referring doctors, they collected outcomes data focussed on biomedical indices and lifestyle measurements such as weight loss, physical activity levels and diet.
We do take...height, weight, waist, hip circumference and then do the six minute walk and the sit to stand test. So we do all of that ‘cause it’s already part of the...programme and that’s what they [external programme provider] ask you to gain for them. (Facilitator 10)

All facilitators perceived that the introduction of their group programmes had reduced the burden of long-term condition management on practitioners and the healthcare system, as the group format was viewed as a resource-efficient method of delivery. It enabled health services to deliver education about self-management of diabetes to multiple patients and get education ‘out of the way’; and hospitals to reduce readmissions and shift patients out of hospitals and into primary care.

It’s reducing the workload of the health professionals I guess... (Facilitator 12)

Facilitators’ accounts of the training that had been provided for the group facilitator role focussed on condition-specific training, a reliance on professional skills and learning on the job. There was little mention of training that contained theory or practical skills related to group enablement or self-management support. See also Table 1.

So I hit the ground running here. I had no real training...but kind of like secondments do, you kind of learn on the job. (Facilitator 5)

2) Education and instruction on the “right” way to manage

When facilitators were asked about the main purpose of their programmes they focused on education and instruction. They discussed this in terms of experts (facilitators) giving people with LTCs the basics of what they need to know and understand in order to self-manage their long-term condition, emphasising physical health, risk and lifestyle behaviour change. Facilitators justified their focus on education as they believed a lack of basic condition knowledge and self-management skills prevails in people with long-term conditions. Also described was the necessity for corrective education due to incorrect health messages in the media.
Even if people say I already know this I don’t think you can just assume that they really, that they do or that they’ve got correct information. (Facilitator 6)

For some facilitators it was important that participants ‘accept’ the facts, reasoning that evidence-based and factual information forms the basics of long-term condition education, as the following quote illustrates:

*The education isn’t going to change, it is educating on health and I mean just because they like or dislike it is really hard to…we’re providing the facts there.* (Facilitator 9)

Some saw group programmes with multiple sessions of long duration (1 - 3 hours over 2 - 12 weeks) as opportunities to provide more education and more time to understand than would be possible in one-to-one consultations. Some facilitators spoke of participants who needed to be told over and over, emphasising notions of knowledge and motivation deficits that needed addressing.

*We’ve just got to be a bit of a broken record until people actually do...what they need to do for good health.* (Facilitator 5)

Facilitators saw education as a means of promoting behaviour change. Yet, they revealed that the programmes’ behaviour change activities such as goal setting were routinely omitted or minimised. To achieve change, these facilitators said they educated about why change was necessary to explain: biomedical causes, health impacts and risks of conditions and unhealthy lifestyles, and benefits of healthy lifestyles. They said that participants needed the right information to be able to make the right decisions, as the following reveals:

*If you don’t have some level of knowledge then you don’t know what it is you’re trying to change [laughs], so how can you...work out any strategies for it...it’s a self-management condition and we don’t want people just going to the doctor having their tests and being told, “Yes, that’s fine.” We want them to actually know.* (Facilitator 3)
In this context, facilitators also discussed being unsure of the value of the programmes’ goal setting activities as shown in this quote:

*I don’t think it’s [goal setting] that effective at all really. I haven’t seen too much success with it.* (Facilitator 13)

Facilitators’ accounts tended not to include recognition of the participants’ prior knowledge, experience, and values as well as the impact of psychosocial factors on participants’ experiences of managing a long-term condition. Self-management elements such as self-efficacy and coping strategies were rarely mentioned. One facilitator spoke of building confidence and self-efficacy in individual participants through treatment dyads within a group format. This included eliciting goals in one-to-one pre-assessments and then providing instruction towards goal achievement over the course of the programme.

*So then I tend to say, “Well the way I can help you is that I know that I can improve your strength and confidence, and what you can do.* (Facilitator 1)

This role tension between providing individualised care and being a group enabler is explored further in the following theme.

3) **Facilitator tensions between role as care provider and enabler**

Facilitators’ reflections on their roles were dominated by care-provider (practitioner) tasks and identities. Some facilitators’ accounts also included one-to-one activities that were little differentiated from the group leader role. Practitioner expertise and (biomedical) evidence were emphasised. Descriptions of their expertise and authority in relation to self-management support tended to be condition specific (e.g. dietitians provided participants with in-depth understandings on carbohydrates and fats and, their effects on HbA1c). Specific expertise was prioritised by facilitators who had designed their own programmes and added to or focused on within commercially acquired
programmes. Group enabling functions of facilitator roles such as promoting commonalities across group members, or any skills and methods they employed for this were mostly absent in accounts.

Some facilitators emphasised their proficiency in addressing individual participants’ risk factors and co-morbidities and providing individualised advice despite working in a group format. The following quote depicts a facilitator’s views on the difficulties of group leadership as related to individuals’ needs.

*I always look at their individual file. ...I’ve got what their A1C is, what their lipids are, what their blood pressure, I know all those parameters, and I’ve been through the files the day before. ...So even though it’s much harder to individualise in a group setting, I still try to...*

(Facilitator 3)

Facilitators were asked about their experiences of being a facilitator and working with people with long-term conditions more generally. They talked about being committed to their role and said they felt a sense of responsibility to help participants achieve better health. Many described their experience of developing close relationships with participants over the course of the programme.

*They always say to me, “I feel confident in you’re looking after me,” and I often wonder what they mean by that, but it might be...that they feel as if I know what I’m doing.* (Facilitator 1)

Yet, co-morbidities and broader psychosocial factors that were recognised by facilitators as limiting some participants’ abilities to follow the directives of the programme were described by some facilitators as hard to tackle. Frustration was expressed that even with their best efforts they were unable to support their participants in addressing broader psychosocial factors.

*It’s a really hard one, because I feel like sometimes you can motivate, you can encourage someone as much as you can to do something that is going to be beneficial for them, but they could almost have all the encouragement in the world...* (Facilitator 7)
Despite the difficulties and challenges facilitators described around their role, an emphasis was placed on needing to keep a positive attitude, and provide hope, motivation, encouragement and support to their participants. Further, all wanted the group environment to be friendly and social and many talked about efforts to enable discussions. Asking open questions was the method described to best achieve this

4) The need for individual responsibility

Facilitators talked about the importance of participant behaviour change to achieve better condition management and control, and how they were giving participants the knowledge and tools that they needed for this. Yet, they said it was up to participants to employ this knowledge and skills in their everyday life. Many used terms such as ‘accountability’ and ‘responsibility’, framing behaviour change as a choice determined by willingness, motivation and the ‘right’ attitude. They provided anecdotes of ‘successful’ participants who had achieved change and were resigned towards participants who did not, despite their own efforts – describing those who returned to their past behaviours as making their own ‘choice’.

You obviously want to see the patients do well and having someone drop out and do their own thing and go back into their habit of doing nothing at home, you feel like it’s a bit…it is a bit sad, but also it’s their choice. (Facilitator 7)

When discussing individual responsibility, some facilitators labelled less ‘successful’ participants as ‘passive’, ‘unmotivated’ or ‘having excuses’, some with little understanding of why they had been referred to the group. Despite facilitators alluding to external reasons for what they saw as some participants’ lack of success in the programme such as the rise of an obesogenic society, poor educational achievement, and level of home support, notions of individual responsibility prevailed.
It’s hard to sort of say to people you know you need to increase your physical activity and improve your diet...so often we don’t see those changes being put into place because of their home environment. (Facilitator 11)

Despite focussing on individual responsibility, most facilitators expressed low expectations for participants being able to achieve behavioural change, saying that for the majority of participants change was mostly minimal and rarely sustained. They spoke of how they suggested small, incremental changes to participants and spent time managing (i.e. reducing) unrealistic and unachievable participant expectations. This they said was easier for both facilitators and participants, reducing the likelihood of failure.

I’m not saying they can’t have success...they have to be realistic about what is success. And I think that’s the message. (Facilitator 5)

When asked, facilitators talked with enthusiasm about how interactions between participants helped to achieve behaviour change through increased motivation, competition, learning and understanding. Further probing however, saw facilitators downplaying the importance of these group interactions. They felt that support and advice from a practitioner was more valuable than from other participants and further, that completion of the programme’s education and structured activities was the main purpose. Many described participant-participant interactions as providing incidental benefits that were secondary to the programme purpose.

I think if we had more time we could let them go a bit longer in terms of talking and conversations...they can probably do that outside if they wanted to. (Facilitator 13)

Discussion

This is the first study to explore the perceptions of the facilitators of group programmes for self-management support, including overall conceptualisations of the programmes as well as perceptions
on programme purpose, development and delivery. We found that the facilitators in our study consistently depicted their group programmes as vehicles for providing pre-determined biomedical education and instruction to people with long-term conditions. There was little or no mention of training to build facilitator capacity for any complexities involved in delivering the group programme format with the result that facilitators adopted an individualised treatment approach approximating one-to-one care. Facilitators felt they were confined by the exigencies of a health care system determining when groups are established, high hospital admissions and waiting lists and further, the need to address the knowledge deficits they described as being a limiting factor in the self-management of people with LTCs. The prevailing notion that a group is a way of getting education ‘out of the way’ privileges the idea of individual care and misses the ethos of group-based programmes.

The facilitators, prioritising instruction and education to the participants sidelined broader aspects such as shared learning, emotional support, problem solving and goal setting. Assuming a low level of knowledge amongst participants, thereby implicitly discounting prior knowledge, and judgements about motivation, attitudes and capabilities was a driver of this perspective, as was a focus on awareness and avoidance of future health problems; i.e. reducing risk. Reliance on the biomedical content appears to have stemmed from a dominant viewpoint that there is a pressing need to educate before further aspects of self-management could be addressed. This reliance on biomedical education aspects may diminish opportunities to address the broader range of components that may enable participants to live well with their condition and is contrary to studies showing multiple component interventions have better outcomes. Yet, facilitators questioned the value of goal setting, a core SMS component, and rarely mentioned aspects such as problem solving and exploration of coping with the emotional and social impacts of living with a LTC. Limited specific training for SMS may have contributed to facilitators’ reliance on biomedical content and avoidance of aspects perhaps peripheral to their professional training.
The group facilitators identified primarily as professional practitioners in the delivery of their group programmes, bringing their clinical background, training and knowledge to their role as well as notions of professional responsibility. The programmes were embedded within healthcare environments (e.g. hospitals, general practice) and this may be partially responsible for a biomedical focus. Facilitators perceived a responsibility to support the systems they were working within by taking the pressure off peers through responding to education needs and focusing on biomedical improvements that could be reported as evidence for programme efficacy. All these factors may have influenced the biomedical focus of the facilitators’ role. Yet, tensions were created as the necessities of their role as a group facilitator were also apparent. These tensions are additional to those already highlighted from practitioners negotiating professional responsibility with patient autonomy in one-to-one self-management support 39. It appears that in the group format, to minimise this discordance, aspects of the professional practitioner role and facilitator role are cherry-picked, creating an environment of individual care in an educational-imperative format.

The facilitators in our study downplayed participant-participant interactions in the group, and hence the support between participants that these interactions may enable, were sidelined. They appeared to devalue mechanisms of support between participants such as emotional support, shared learning and sharing of experience. This is despite the group programmes in our study being for single conditions and hence comprised of participants with similar experiences. The combination of the facilitators’ beliefs in the basic education needs of participants and the lack of specific facilitator training for groups may have lessened the value they placed on group interactions in the programmes. In light of this, it was surprising that facilitators spoke of the value gained from participants interacting with each other despite not being prepared to further invest time into them beyond what occurred incidentally. Facilitating support between participants is inherently unstructured and this requires a relinquishing of control 40, absent in the facilitators responses in the current study. Promotion of shared learning and supportive relationships between group participants would seem to be integral to this format and thus an area for immediate attention 29.
Strengths and limitations

A strength of our study is that diverse programmes from everyday practice were sampled. Whilst only 13 facilitators were interviewed for this study, there was diversity in healthcare practitioners and context in this sample. However we will not have captured the full range of experiences and perceptions of facilitating group self-management support programmes. We limited our sites to those with HCP facilitators (a common format) and note that other forms of self-management support programmes exist with different formats and practitioner types such as peer facilitators and for other single and generic long-term conditions. Differences between facilitator profession types or length of experience were beyond the scope of this paper.

Implications for clinical practice

Our study has revealed the perspective of facilitators of group self-management programmes for people with LTCs, a previously underreported perspective. The facilitators in our study conceptualised their programmes as education and instruction vehicles, setting up their participants for post-programme behaviour change and individual responsibility. This runs contrary to long-term condition policy and models of self-management support that advocate for programmes that have education as only one component of broader self-management support that also promotes and applies problem solving skills, building of self-efficacy and goal setting towards medical, social and emotional aspects of long-term condition management. Our sample shows an example of a disconnect at the point of implementation of LTC policy. Further, we revealed that the potential benefits of being in a group with other people who share similar experiences, such as social support and social learning may not necessarily be understood nor valued by practitioners.

The limitations and contradictions of current practice presented in the views of the facilitators in our study point to, with respect to group self-management support programmes, a potential weakness in the realisation of self-management outcomes. Multiple levels of health system policy, implementation and the training of healthcare practitioners may be implicated. A greater
understanding of all the components of self-management support models that are prominent in both policy and theory, may lead to a better realisation of the overall aims of supporting the self-management of those with long-term conditions. This paper supports the need for deep reflection on the current practice and purpose of group self-management support programmes. To be relevant self-management support in groups must reflect objectives broader than biomedical education and instruction to support the self-management needs of participants.

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