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Title: Participants' experiences of and perceived value regarding different support types for long-term condition self-management programmes

Abstract

Objectives

Health professional led group programmes are a common form of long-term condition self-management support. Much research has focused on clinical outcomes of group participation, yet there is limited research on how group participants perceive and experience the support they receive. We aim to identify the different types of support that participants receive from both facilitators and other participants, and how they value this support.

Methods

Semi-structured interviews were conducted with 20 participants taking part in a self-management group programme for a long-term condition (obesity, type 2 diabetes or chronic obstructive pulmonary disease). Data pertaining to support types were deductively identified through a social support framework (guided by Cohen (2004), Thoits (2011)) prior to interpretive thematic analysis.

Results

Participants identified information and emotional support from both facilitators and other participants as complementary yet distinct. Facilitators' support came from professional training and other participants' support reflected the contextual, lived experience. Professional interactions were prioritised, constraining opportunities for participant-participant support to be received and exchanged.

Discussion

We identified a key gap in how self-management support is enacted in groups. Engaging participants to share experiential knowledge will make group support more relevant and mutually beneficial to participants living with a long term condition.

Key words: self-management, group programme, long-term condition, qualitative

Introduction

The increasing prevalence of long-term conditions (LTCs) has created new challenges for health systems and health professionals in how to provide self-management support for people living with these ongoing and mostly progressive conditions. An often-cited aim is for health professionals to provide person-centred support in partnership with their patients with LTCs, by harnessing and enhancing patients' own capabilities to self-manage¹⁻⁴. Group programmes are a common format for the provision of self-management support in many countries including Australia. There is evidence that self-management support group programmes can improve clinical outcomes and have a positive effect on the activities of daily living^{5,6}.

Social science scholarship has critiqued self-management support programmes for ignoring broader support provision and instead, prioritising problem health behaviours, clinical outcomes and public cost savings⁷⁻⁹. Overuse of the psychological constructs of self-regulation and self-efficacy focusses attention on individual responsibility for behaviour change with negative ramifications including harm for those with less capabilities or social capital as well as abdication of ongoing state responsibility¹⁰⁻¹².

There is also evidence showing that these programs have limited impact for more marginalised groups in the population (e.g. ethnically diverse and socially and economically disadvantaged), who should benefit the most. This is because they tend to ignore the impact and relevance of people's social context and priorities^{13,14}. For example, an individual living with a LTC may prioritise maintaining valued social relationships, roles and identities, whereas symptom management and clinical outcomes may be less personally relevant to them^{12,15}.

Self-management support is articulated in national and international health policy as a way to extend the scope of LTC healthcare delivery, giving prominence to people's needs and including

social and emotional dimensions alongside medical and clinical aspects of LTCs^{1, 16}. It has been delivered using approaches based on different models^{5, 17-22}. The provision of group self-management support is typically facilitated by health professionals such as nurses, dietitians and physiotherapists. Evidence shows improved health outcomes for condition markers such as blood sugar levels in diabetes, health behaviour changes and utilisation of healthcare, although these are usually small and not sustained long-term^{5, 13, 23-26}. Research also shows the potential of group programmes for providing an environment of peer support, where participants can share experiences and gain condition-specific knowledge and strategies for self-management²⁷. A recent systematic review²⁸ of the experiences of participants in self-management groups revealed the importance of social support, belonging, connectedness and shared learning with other group participants. However, research on the experiences of group facilitators of self-management support shows that their focus remains predominantly on providing evidence-based education and instruction for health behaviour change, rather than on group member interactions and peer support^{5, 29, 30}.

There is no universally recognised definition of self-management support and the notion of what constitutes support is still under-developed. In particular there has been very limited research on how group participants perceive and experience support in group programs, how they describe and value the different kinds of support provided by facilitators and other group participants, and how they mobilise this support to help live with and manage their condition.

In this paper, we draw on Cohen's (2004) framework of support which suggests that support encompasses three main types – informational, instrumental and emotional. Informational support refers to information, advice or guidance; instrumental support refers to tangible assistance; and emotional support to 'expressions of empathy, caring, reassurance, and trust' and 'venting'³¹. We also draw on the theoretical work of Thoits (2011) who proposes that the support provided by individuals with similar experiences is valued for their experiential knowledge and understanding of

the ‘many dimensions and nuances’ of an individual’s lived experience and situation ³². Similar others show empathy, and provide information and advice that individuals find relevant, because they have similar experiences ³²⁻³⁴. Similar others can also act as role models and comparators who can shape coping responses and provide hope that proposed courses of action will be beneficial ^{32, 35}.

In the context of health professional-led self-management programmes, where there is potential for support from both group facilitators and from group participants sharing similar experiences, there is still little known about what type of support participants receive from facilitators and participants, and what support they value. In this qualitative paper our aim is to identify the different types of support that group participants in self-management support group programmes receive and exchange between both facilitators and peers, and how they value this support.

Methods

Approach

This paper draws on semi-structured interview data from individuals participating in self-management group programmes in New South Wales, Australia. Interviews explored participants’ experiences and views of self-management support while participating in the programmes. We designed a qualitative research study, drawing on an interpretive approach to data collection and analysis. Ethics approval was obtained from Sydney Local Area Health District Human Research Ethics Committee (Protocol no: X15-0214), and from the University of Sydney Human Research Ethics Committee (Project no: 2016/898).

Sample

Group programmes (n=6) for one of three LTCs - chronic obstructive pulmonary disease, type 2 diabetes or obesity - were purposively selected for diversity across metropolitan and regional locations and hospital and community-based settings. All programmes were led by a health professional (see Table 1 - programme characteristics). All group participants (n=57) of these programmes were invited to participate in individual interviews.

Table 1. Programme characteristics

Site	Location	Condition	Facilitator types	Participant no. (at first session)
1	Large metropolitan hospital outpatient gym	COPD	Physiotherapist	10
2	Small metropolitan hospital outpatient gym	COPD	Physiotherapist	7
3	Large metropolitan hospital outpatient room	Diabetes type 2	Dietitian	9
4	Suburban general practice	Diabetes type 2	Dietitian and exercise physiologist	5
5	Large metropolitan hospital outpatient room	Obesity	Physiotherapist, nurse, psychologist, dietitian	20
6	Rural, community hall / hospital meeting room	Obesity/ healthy lifestyle	Dietitian and exercise physiologist	6

Recruitment

A researcher introduced the study to participants during the programme, describing the purpose and what participation would involve. Interested participants were given an information sheet and invited to participate in an interview. All participants provided written consent prior to interview.

Data collection

In-depth, semi-structured interviews were conducted face-to-face or by telephone (Dec 2015 - Apr 2017). An interview guide was developed to explore experiences of participation in group programmes informed by LTC support literature and a systematic review of the qualitative group self-management literature²⁸. Interviews explored experiences of living with and managing LTCs, experiences of participating in the group programme and interactions with group facilitators and other participants. Interviews lasted between 60-90 mins, were audio recorded and transcribed verbatim by professional transcribers. Data were de-identified and pseudonyms allocated.

Data analysis

Qualitative data software (nVivo 11) was used to manage and organise the data. Data were thematically analysed using a combination of deductive and inductive analysis. Interview transcripts were read repeatedly and data pertaining to support were identified and categorised into the three theoretical component types of support provision – instrumental, informational and emotional (table 2) ^{31,32}. In this deductive process, we were also sensitive to descriptions of perceived versus received support and the source of support. Inductive thematic analysis of each category explored how participants talk about the value and meaning associated with support experienced during the programme, their views on different sources and types of support and how they were accessed in the groups. Trustworthiness and credibility were enhanced by: two authors from different disciplines and levels of experience coding separately; regular comparison, challenging of interpretations and revisiting of raw data using an iterative back and forth process; refining and discussion of emerging themes with the broader research team; and use of an audit trail to document processes, decisions and dispute resolution ³⁶. The presentation of findings includes exemplar quotations of the themes.

Table 2. Types of social support (adapted from Cohen 2004, Thoits 2011 ^{31,32})

Instrumental	Informational	Emotional
Provision of material aid to deal with daily tasks or financial assistance	Provision of relevant information in the form of advice or guidance to deal with problems and cope with current difficulties	Expressions of empathy, caring, reassurance and trust provision of opportunities for emotional expression and venting

Results

Table 3. Participant characteristics

Characteristic	Number
Gender	
Female	10
Male	10
Age	
Average	59
Range	27-80
Median	66
Condition	

Diabetes	6
Obesity	8
COPD	6
Education level	
School year 10 or below	2
School year 12 or equivalent	7
Trade certificate	5
University degree	5
Not disclosed	1
Employment status	
Employed full-time	2
Casual employment	2
Not currently working*	16

* Note: Not currently working includes retirement (n=11)

Participants (n=20) across six diverse programmes (see table 3), provided similar overarching notions in their responses when discussing support in the programmes. All had been referred to the single condition programmes by a medical practitioner. However, they also revealed emotional and social issues during the interview, as well as concerns about managing other LTCs. Participants discussed informational and emotional but not instrumental support from the group programme. They saw group facilitators and other participants as contributing different yet complementary forms of informational and emotional support for living with a LTC. Participants described filtering information from both other participants and facilitators, choosing what was valid and useful to them. They also highlighted that although they valued time in the sessions for interaction with other participants, these interactions were often shut down or not encouraged by facilitators. We cover each of these main themes in turn.

Complementary forms of informational support

Participants described health professional facilitators as focused on ‘factual’ information and advice. They positioned the facilitators as having expert knowledge in medical aspects of self-management of LTCs such as condition physiology, test results, medications and recommended foods and exercises. They appreciated the facilitators’ interest and time studying chronic condition care. Information and advice provided by facilitators was trusted, respected and endorsed by participants (e.g. ‘she has legitimate answers to legitimate questions’ (Rose, 69 years, COPD)). Participants

privileged facilitators' knowledge by stating that they had 'the right' information and advised the 'correct' course of action. This can be seen in the following excerpt from Gary where the biomedical or professional knowledge of the facilitator is legitimised, in part because of its exclusivity (i.e., controlled by health professionals). Gary mobilises the information that he understands, describing this as a strong motivating factor in doing strenuous exercise.

[The facilitator might say] "I want you to do this." And I'll do it because I respect his knowledge. He knows what he's talking about. And I know I've got to push myself. ... that's my motivator, I want to see my heart rate improve, because that's going to help the arteries, it's going to do a lot of good. (Gary, 73 years, COPD, site 2)

At times, however, participants perceived that the information provided by facilitators was overwhelming ('too much' information), irrelevant and lacking insight into their personal circumstances. The following quote illustrates how one-way delivery of information led to disengagement:

This is a very formal, a more rigid educational [programme]...They're not finger wagers, but it's a, professorial at the lectern, rather telling us what we need to know rather than letting us discover what we need to know. (Dan, 52 years, obesity, site 5)

When group facilitators positioned themselves as high status or authoritative many participants felt impeded from developing knowledge and discovering ways themselves to self-manage. Some participants' accounts suggested that they felt like passive recipients of information, 'we just sit and listen to what he says' (Ken, 79 years, diabetes, site 4), when they wanted their own expertise and capabilities for independent learning to be recognised by facilitators and integrated. Fred, for example exclaimed 'we're not kids' and suggested many aspects of the information provided by facilitators were common knowledge, and underestimating participants' knowledge limited other opportunities for informational support.

They say, 'oh yeah that fats no good for me or that much sugar is no good for me'. There's no need to go to the program to know that, because you can read it yourself. (Fred, 72 years, diabetes, site 4)

In contrast, participants described the informational support gained from other participants as different from that of facilitators and complementary – it filled gaps in the facilitators' informational support. Other participants provided informational support gained from their experience of living with and managing LTC(s), i.e. experiential ('lay') knowledge, that was more personally relatable and relevant to participants' own circumstances, needs, experiences and challenges. This knowledge was predominantly about practical strategies and information, and personal accounts of what has worked or not, and less narrowly focused on recommended treatments. Other participants were also more likely to provide information about managing the wider social and emotional aspects of self-management such as uncertainty, negative emotions and feelings, interpersonal relationships and relationships with other health professionals.

Something else to think about, ponder over, sort of think well that's not for me or, yeah, I could do that, that's a great idea. ...I'll look into that or, start thinking of questions, and getting answers. (Rose, 69 years, COPD, site 1)

They identified this as a key 'gap' in the informational support that was provided by group facilitators, who provided more generic information, but had limited understanding about the intricacies and specificities of living with and self-managing LTCs. Kevin believed that health professionals are not fully aware of how burdensome it is for people with diabetes to adopt and sustain a restrictive diabetic diet.

[Health professionals] can empathise all they want, but they don't know what it's like ... if it was someone suffering diabetes sitting there, then she is giving us information from her own experience. Being a diabetic, that would make a quantum leap because then they're more believable. ... there's a difference between a dietician managing their life and eating healthy and

having a proper meal size, because they've done it because they want to. They haven't had to do it because they've got diabetes ... it is harder for someone to do because they have to. (Kevin, 62 years, diabetes, site 3)

Similarly, Bill contrasted the theoretical knowledge from facilitators and the 'practical' knowledge from participants, revealing how he listened to other participants' experiences and used this information alongside the responses of the facilitator to form his own understanding.

Actual people with the disease or whatever, it sort of resonated more with me...just finding out, hearing more, and learning about something from someone who's not read it in a book, who's actually living it... I'd like to hear the theory from [the facilitator], but the practical stuff from other people. (Bill, 31 years, diabetes, site 3)

Being encouraged and feeling safe: valuing emotional support from facilitators and peers

Participants described the group environment as 'welcoming', 'comfortable' 'safe', and 'reassuring'.

They felt emotionally supported by both group facilitators and other participants, yet distinguished between the nature of such support. Emotional support from facilitators was typically more explicit – it was described as being encouraged, listened to and responsive to their concerns. In contrast, the emotional support gained from other participants was described as more inherent or 'felt' – as a feeling of belonging, reassurance, acceptance and safety of being among others with similar experiences. Emotional support from facilitators was further described as being 'personable', 'empathic' and 'positive'. Relationships with facilitators were described as trusting and non-threatening. Many emphasised that they were treated as a 'person' rather than a 'patient' (contrasting past experiences with other health professionals). For example, Monica said she could confide in her facilitator about anything and be listened to and supported rather than judged and blamed.

I confide in them that I can't stop eating, I cannot stop eating. So she gave me her email address, and I've emailed her what I eat for a whole week. And she's going to go over it and sit down and talk to me and explain. (Monica, 36 years, obesity, site 6)

Others similarly felt comfortable to expose vulnerabilities or fragilities to individual facilitators, without fear of being shamed, embarrassed or criticised. Some gained reassurance knowing social and emotional impacts of living with LTCs are 'normal' experiences.

I can ask [the facilitator] stuff about this disease that my doctor doesn't fill... Like is it normal to feel depressed; is it normal to feel you know like isolated...she gives you answers, or she gives you skills to deal with stuff...She has great experience, and she's got empathy, she treats everybody as an individual, which is really, really nice. She remembers your name and she listens to you. She reassures you that you're not going crazy, and that it's normal to feel this way, people do feel this way, so you're not alone. (Rose, 69 years, COPD, site 1)

I find them [facilitators] wonderful,...I think what it does is it allows me to be frail, you know, it allows me to have my own frailties without feeling embarrassed by them. (Mark, 68 years, COPD, site 1)

In contrast, the emotional support exchanged between group participants was rarely as overt as from facilitators. Apart from a couple of instances – encouragement during exercise activities, in most cases- participants described emotional support from other participants as *felt*, or in the words of Gary, 'subliminal ...you're not conscious of supporting someone or being supported'. They felt they were among peers similar to them because of shared experiences living with LTCs. Knowing their peers faced similar challenges and 'struggles' was described as a 'leveller' and led to feelings of inclusivity. Perceiving no hierarchies contributed to a 'non- threatening', open and inclusive space, and a feeling of 'safety'. Even though this was not demonstrated explicitly, participants felt peers were non-judgemental because of shared experiences, illustrated by Ruby and Gary:

I know people are doing the same thing, and struggling the same as me, and want to lose the weight like me, and are doing the same exercises...I get more out of it. 'Cause I know that I've got the support...they're [other participants] not judging me on how I look, or how I'm doing things, they're there to help me, they're there to actually give me the support I needed. ... not just giving me support because they feel pity for me. (Ruby, 27 years, obesity, site 6)

You might have a million dollars and the next person's got nothing but we're still in the same boat. ...And that's the leveller...we're all there because we have a problem. (Gary, 73 years, COPD, site 2)

This sense of belonging and acceptance, not always present in spaces outside of the group, allowed participants to compare their situation to others and feel less 'alone', 'hopeful' (seeing others doing well), and that their experiences of illness were 'normal' and shared.

Most things that [other participants] Ken and Michael said that they do, I'm about the same. ...Makes me feel that I'm normal...that I'm the same as other people... I like it. (Fred, 72, diabetes, site 4)

What I like about being in the group is that it allows me to be more accepting of myself and my own limitations because I can see the limitations of other people. So I can be here and I can see some people are stronger than me, some people are weaker than me, some people breathe better, some people breathe worse, it just allows me to be in sort of like a peer group with the chests. (Mark, 68 years, COPD, site 1)

Participants also described being able to express feelings, emotions and frustrations to an understanding audience. They felt confident other participants would be accepting. For example, Mark talked about being 'allowed' to express his feelings:

It's supportive talk in a sense that it might be just, "oh, God that's hard, I'm buggered" you know, that sort of level of conversation which is fine. ...it just allows you to say how you feel and you know that they understand completely. (Mark, 68 years, COPD, site 1)

Constraining opportunities for peer support through group interactions

Opportunities for peer support through participant interactions, though seen as important to participants, were perceived to be shut down or not encouraged by facilitators. Thus they were few and mostly 'ad hoc', often fitted in between content or activities directed closely by the facilitators. Most participants felt they would have gained from more opportunities to hear from, and talk with, other participants. A few however, said they actively avoided interactions with others in the group fearing unhelpful negative emotions may be triggered.

Participants perceived that the facilitators and programme structure prioritised facilitator-directed programme aspects such as education, instruction and activities (individual exercises or workbooks). They felt that support from other participants was invisible to facilitators. Facilitators were described as not giving opportunities or space for group interactions or at times active in shutting down interactions. Numerous examples of this include Anna, who perceived facilitators were discouraging of participant-participant interaction and questioned the room configuration in rows, not facing each other and Deb, who stated she had gained little knowledge of the other participants.

the way the room is set up.just looking forward. So, there's not much interaction that way. ...I don't know why they do it that way...it's less intimidating for people?...it doesn't make for people interacting. (Anna, 52 years, obesity, site 5)

We say good morning to each other but I don't really know the people that were there. I don't know anything about them at all. (Deb, 69 years, COPD, site 2)

Other participants who felt restricted in their opportunities for discussions wondered what might have been missed by not interacting more with others. Some would have liked to have heard more

of others' feelings and their experiences of coping, suggesting the struggles of others provides context for a more favourable self-perception:

It's more normalised. ...The other people are struggling with their own issues, the real people. ...[However,] there's not a chance for interaction and question asking, and how someone else has overcome. ...you're able to pick up little gems from other people. But again, here, I think this is more a...and it's not a finger wagging, but it's kind of, this is the knowledge you need to have.

(Dan, 52 years, obesity, site 5)

A few participants felt an absence of opportunities themselves to express feelings and coping to other participants. They believed this would have benefitted emotions such as feeling low and isolated. For example, Rose regretted missing the supportive benefits of others. Warren was willing to come early or stay back if the opportunity presented itself:

The only thing that I regret in here is that I come in and I just do my sheet myself, I do my exercises, like if I need help I can go to her [the facilitator] if there's a problem ...In a way I sometimes think when I've been really low, I think if I just had somebody to talk to about this feeling, I might feel better. But I don't, so then I talk to [facilitator]. ...and she said, "Yeah, this is when you need to go and see your GP." (Rose, 69 years, COPD, site 1)

Even if they had ten minutes after. I know people got to go to pick their kids up but even if they come ten minutes earlier you know and somebody just sit down and just say how hard'd you think it was this week it'd be alright. Because a lot of them'll say well, it'd probably be hard for them this week. (Warren, 33 years, obesity, site 6)

A few participants spoke of their reluctance to share their experiences with their health condition, yet valued the 'little chats' with other participants about daily activities and common interests.

These participants avoided talking about LTCs in part to avoid negative emotions that this could

trigger. As such, incidental interactions served a different function in that they relaxed and helped participants to 'settle in and feel part of the group' and made it 'fun':

It relaxes you. I think it's important.... We're not talking about "oh how's your lungs", you know. ...No-one ever says, 'oh yeah I'm bringing up, you know this' and "coughing and spluttering over my husband". It's never mentioned. ...we know why we're all there. We just chat about other things...about life. ...No you don't talk about your illness. (Gary, 73 years, COPD, site 2)

Discussion

This study explored the perspectives of people participating in a diverse range of health professional-led group programmes providing support for LTC self-management, about the nature and type of support they received. Applying a social support theoretical framework³¹ to our in-depth exploration of the experience of group programme participation has given new explanations for how participants perceive and value 'support' in this format. Our findings show that participants gained informational and emotional support from both health professional facilitators and other participants. A key finding is that participants distinguished between the different types of knowledge and emotional support offered by facilitators and peers in the groups, as well as the different origins and justifications of the types. Further, these different types of support had different meanings and value to them and, together, they found the different types of support to be complementary. Participants felt that one source of support had limitations, and that a broader range of support had been gained in the groups than in other healthcare and social encounters. However, opportunities for supportive interactions between peers were few as participants perceived them to have been constrained by health professional facilitators who prioritised health professional support.

Informational support from facilitators was seen as factual, providing legitimate answers to participants. Yet, when presented as didactic or authoritarian education, it disempowered participants and reduced their engagement with programmes, confirming previous findings about

the low value of this type of education ⁵. In contrast, support received from other participants was grounded in lived experience and rich with opportunities about possible strategies and real examples of successes and failures for self-management. People valuing and seeking experiential knowledge from similar others is not a novel finding and the self-help movements and online patient experience boom has been well documented ³⁷⁻³⁹. Indeed, governments and other organisations have themselves become promoters as the evidence for benefits have increased ³⁸. Our study suggests that in the context of formal self-management programmes led by health professionals, participants have the opportunity to evaluate both professional expertise and experiential knowledge to form a broader, more relevant understanding, of their own situation and knowledge needs ⁴⁰. Further, the perceived limitations of both health professional facilitators and of other participants are reduced by the presence of the other. Participants, when speaking of this complementarity, appeared to be more engaged with the programmes and their self-management than when speaking of expert information only.

As with informational support, emotional support enabling participants to feel safe and reassured also differed by source. Emotional support from facilitators was perceived as overt and attentive, participants valued the professional care, reassurance and encouragement, whereas from other participants it was inherent and described as 'felt' among peers with commonalities and shared understandings. Thoits and others have suggested that perceived emotional support, such as that spoken about by the group participants, is (paradoxically) stronger and more consistently beneficial to health than received (overt) emotional support ³¹. Our study participants' responses were about the value of having emotionally 'safe' opportunities to chat with and observe others, and a number spoke about value in emotionally supportive non-condition interactions. Perhaps health professional oversight of face-to-face contact in this format is a unique enabler for people prone to isolation, and where other emotional support formats such as professional, online, self-help or peer groups do not appeal ^{38, 39}.

Studies of self-management participants' experiences have previously reported limits to opportunities for peer interaction in group programmes²⁸. Our study found participants viewed being with peers as providing supportive processes distinct from those of health professionals. Thoits suggests support from similar others directly affects physical and mental health and indirectly buffers harmful physical and mental effects³². However, research has shown health professional facilitators do not always prioritise this form of support and professional authority, evidence-based education and narrow biomedical conceptualisations of self-management support prevail^{9, 29, 30}. Explanations may include a lack of group-specific facilitator training²⁸ and health professionals being uncomfortable or even threatened with changes to power structures needed to incorporate and trust patient expertise^{41, 42}.

The participants in our study, as in other studies⁴³, revealed they had compared themselves with others, which assisted with feelings of normality and perceived greater sense of hope. Uniquely in this study, participants reported that through these processes of perceived support from others they felt more motivated and engaged with their health. These outcomes should be of interest to researchers, practitioners and policy makers in the ongoing quest for patient engagement and activation with self-management^{44, 45}.

Strengths and limitations

A study strength was that we conducted purposive sampling in order to gain breadth and richness of experience across a range of conditions, programmes, gender and demographics. The majority of participants were unemployed (n=5) or retired (n=11) perhaps due to programmes being free (publicly funded) and conducted on weekdays: interviews did not explore the potential of LTCs as causative of unemployment. Limitations included that participants self-selected into the study and this may mean that other viewpoints were not captured in our data, such as from those who feel group self-management is unsuitable, who dropped out of the programme or were less engaged. In addition, ethnicity, socio-economic age and gender variation may be elucidated in further studies of

specific populations. A further limitation is that only one interview was conducted per participant. Future studies may wish to explore other group programme settings, use multiple time points before, during and after programmes and explore differences between different groups related to programme delivery, and how this impacts on participant experience.

Implications for clinical practice

Participants exposed some of the limitations of formal self-management support provided by health professionals in group programmes, as well as some opportunities. The group programmes in our study were perceived by participants as prioritising health professional and medical authority over exploration and nurturing of support for mutual benefit among the group participants. The ‘invisibility’ of the support that participants perceived and valued highly from peers may pose difficulties for health professional facilitators in the programme frameworks and medical contexts they operate within, which frequently use measurable biomedical outcomes to define success^{5, 29}. Practitioners facilitating group self-management support programmes should be aware of the limitations inherent in professional expertise revealed in this study to people seeking support with self-managing LTCs. Finding the right balance may prove challenging to facilitators; guidance through theoretical scholarship into the purpose of self-management support^{1, 9}, peer support^{31, 32, 46, 47}, patient experience of LTCs self-management⁴⁸ and patient-centred care⁴⁹ may be beneficial. This study suggests that allowing space for making explicit the inherent support of peers and promoting experiential knowledge should make group self-management support more relevant to participants. This should be key to health systems and health professionals with aspirations to positively affect the lives of people with LTCs.

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References

1. Entwistle VA, Cribb A and Owens J. Why Health and Social Care Support for People with Long-Term Conditions Should be Oriented Towards Enabling Them to Live Well. *Health Care Anal* 2018; 26: 48-65.
2. Nolte E and McKee M. *Caring for people with chronic conditions: a health system perspective*. UK: Open University Press McGraw-Hill Education; 2008, p.4.
3. Wagner EH. Chronic disease management: What will it take to improve care for chronic illness? *Eff Clin Pract* 1998; 1: 2-4.
4. Dunston R, Lee A, Boud D, et al. Co-production and health system reform—from re-imagining to re-making. *Aust J Publ Admin* 2009; 68: 39-52.
5. Taylor SJ, Pinnock H, Epiphaniou E, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS—Practical systematic Review of Self-Management Support for long-term conditions. *Health Serv Deliv Res* 2014; 2.
6. van het Bolscher-Niehuis MJT, den Ouden MEM, de Vocht HM et al. Effects of self-management support programmes on activities of daily living of older adults: A systematic review. *Int J Nurs Stud* 2016; 61: 230-247.
7. Kendall E, Ehrlich C, Sunderland N, et al. Self-managing versus self-management: reinvigorating the socio-political dimensions of self-management. *Chronic Illn* 2011; 7: 87-98.
8. Rogers A, Bury M and Kennedy A. Rationality, Rhetoric, and Religiosity in Health Care: The Case of England's Expert Patients Programme. *Int J Health Serv* 2009; 39: 725-47.
9. Morgan HM, Entwistle VA, Cribb A, et al. We need to talk about purpose: a critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expect* 2017; 20: 243-259.
10. Thille P, Ward N and Russell G. Self-management support in primary care: Enactments, disruptions, and conversational consequences. *Soc Sci Med* 2014; 108: 97-105.
11. Kendall E and Rogers A. Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management Programme. *Disabil Soc* 2007; 22: 129-143.
12. Morden A, Jinks C and Ong BN. Rethinking 'risk' and self-management for chronic illness. *Soc Theory Health* 2012; 10: 78-99.
13. Rogers A, Kennedy A, Bower P, et al. The United Kingdom Expert Patients Programme: results and implications from a national evaluation. *Med J Aust* 2008; 189: S21.
14. Ong BN, Rogers A, Kennedy A, et al. Behaviour change and social blinkers? The role of sociology in trials of self-management behaviour in chronic conditions. *Sociol Health Ill* 2014; 36: 226-238.
15. Townsend A, Wyke S and Hunt K. Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Ill* 2006; 2: 185-194.
16. Australian Government Department of Health. Flexible Fund Guidelines - Chronic Disease Prevention and Service Improvement Flexible Fund, <http://www.health.gov.au> (2014, accessed 30 Aug 2018).
17. Pearce G, Parke HL, Pinnock H, et al. The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility. *J Health Serv Res Policy* 2016; 21: 73-82.
18. de Silva D. *Evidence: Helping people help themselves. A review of the evidence considering whether it is worthwhile to support self-management*. London: The Health Foundation; 2011.
19. Coster S and Norman I. Cochrane reviews of educational and self-management interventions to guide nursing practice: a review. *Int J Nurs Stud* 2009; 46: 508-528.
20. Barlow J, Wright C, Sheasby J, et al. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* 2002; 48: 177-187.

21. Battersby M, Von Korff M, Schaefer J, et al. Twelve evidence-based principles for implementing self-management support in primary care. *Jt Comm J Qual Patient Saf* 2010; 36: 561-570.
22. Lorig K. Chronic disease self-management program: insights from the eye of the storm. *Front Public Health* 2015; 2: 1-3.
23. Deakin TA, McShane CE, Cade JE et al. Group based training for self-management strategies in people with type 2 diabetes mellitus. *Cochrane Database Syst Rev* 2005; 2: CD003417.
24. Warsi A, Wang PS, LaValley MP, et al. Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. *Arch Intern Med* 2004; 164: 1641-1649.
25. Zwerink M, Brusse-Keizer M, van der Valk PD, et al. Self management for patients with chronic obstructive pulmonary disease. *Cochrane Database Syst Rev*. 2014; 3: CD002990.
26. Lorig KR, Ritter P, Stewart AL, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care* 2001; 39: 1217-1223.
27. Stenberg U, Haaland-Øverby M, Fredriksen K, et al. A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with chronic illness. *Patient Educ Couns* 2016; 99: 1759-1771.
28. Hughes S, Lewis S, Willis K, et al. The experience of facilitators and participants of long term condition self-management group programmes: A qualitative synthesis. *Patient Educ Couns* 2017; 100: 2244-2254.
29. Hughes S, Lewis S, Willis K, et al. How do facilitators of group programmes for long-term conditions conceptualise self-management support? *Chronic Illn* Epub ahead of print 1 August 2018. DOI:10. 1177/1742395318792068.
30. Sadler E, Wolfe CDA and McKevitt C. Lay and health care professional understandings of self-management: A systematic review and narrative synthesis. *SAGE Open Med* 2014; 2: DOI: 10. 1177/2050312114544493.
31. Cohen S. Social relationships and health. *Am Psychol* 2004; 59: 676-684.
32. Thoits PA. Mechanisms Linking Social Ties and Support to Physical and Mental Health. *J Health Soc Behav* 2011; 52: 145-161.
33. Kennedy A, Reeves D, Bower P, et al. The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *J Epidemiol Community Health*. 2007; 61: 254-261.
34. Koetsenruijter J, van Eikelenboom N, van Lieshout J, et al. Social support and self-management capabilities in diabetes patients: An international observational study. *Patient Educ Couns* 2016; 99: 638-643.
35. Rogers A, Vassilev I, Kennedy A, et al. Why less may be more?: A mixed methods study of the work and relatedness of 'weak' ties in supporting long term condition self- management. *Implement Sci* 2014; 9: 1-11.
36. O'brien CB, Harris BI, Beckman JT, et al. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. *Acad Med* 2014; 89: 1245-1251.
37. Borkman T. Experiential knowledge: A new concept for the analysis of self-help groups. *Soc Serv Rev* 1976; 50: 445-456.
38. Ziebland S and Wyke S. Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *Milbank Q* 2012; 90: 219-249.
39. Allen C, Vassilev I, Kennedy A et al. Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers. *J Med Internet Res* 2016; 18: e61.
40. Leventhal H, Brissette I and Leventhal EA. The common-sense model of self-regulation of health and illness. In: Cameron L and Leventhal H (eds) *The self-regulation of health and illness behaviour* London: Routledge, 2003. pp. 42-65.

41. Snow R, Humphrey C and Sandall J. What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. *BMJ Open* 2013; 3: e003583.
42. Greenhalgh T, Snow R, Ryan S, et al. Six 'biases' against patients and carers in evidence-based medicine. *BMC Med* 2015; 13: 200.
43. Rogers A, Gately C, Kennedy A et al. Are some more equal than others? Social comparison in self-management skills training for long-term conditions. *Chronic Illn* 2009; 5: 305-317.
44. Australian Health Ministers' Advisory Council. National Strategic Framework for Chronic Conditions. Report, Australian Government Department of Health and Aging. Canberra, 2017.
45. Hibbard J and Gilbert H. Supporting people to manage their health: An introduction to patient activation. Report, The King's Fund, London, UK, May 2014.
46. Embuldeniya G, Veinot P, Bell E, et al. The experience and impact of chronic disease peer support interventions: A qualitative synthesis. *Patient Educ Couns* 2013; 92: 3-12.
47. Simmons D, Bunn C, Cohn S et al. What is the idea behind peer-to-peer support in diabetes? *Diabetes Manag* 2012; 3: 61-70.
48. Demain S, Goncalves AC, Areia C, et al. Living with, managing and minimising treatment burden in long term conditions: a systematic review of qualitative research. *PLoS One* 2015; 10: e0125457.
49. Mead N and Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000; 51: 1087-1110.

Appendix 1. Interview guide questions

1. Living with a LTC

Tell me a bit about yourself

What kind of things do you do to manage your condition?

Has the way you manage your condition changed over time?

2. Group program discussion

How did you come to be in this group program?

Can you tell me a bit about your experiences of being in the group program?

What do/did you hope to get out of attending this course?

What do you think the group leader's role is?

How have you found the course material?

3. Plans for your health

What plans do you have for your future health?

After you finish the program, how do you think the way you manage your [] will change? Why?

How do you feel about the future when living with []?