# Title: Participants’ experiences of support through long-term condition self-management programmes

Abstract

Objectives

Health professional led group programmes are expected to combine professional support with social support between participants. Few studies have investigated how group participants view the support available to them and what support they gain from participation. We used a social support framework to explore what support group programme participants perceive.

Methods

A qualitative design included in-depth semi-structured interviews with participants (n=20) from six diverse self-management support group programmes (of obesity, diabetes and COPD). Analysis of transcribed data was thematic. .

Results

Differing informational and emotional support was provided by health professional facilitators and other participants, and participants considered the differences as both valid and important. The informational support included both factual and experiential knowledge, and the emotional support included overt professional and inherent ‘felt’ support among peers with shared understandings. Opportunities for supportive interactions with peers however, were few and not encouraged by facilitators.

Discussion

Limiting experiential knowledge and emotional support among participants by prioritising health professional support and medical authority reduces opportunities for what participants value and view as different, important and equally valid in their experience. Enabling broad support from both sources should be key to providing relevant group programmes.

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

# Introduction

The increasing prevalence of long-term conditions (LTCs) has triggered new challenges for health systems and health professionals in terms of how best to provide support for individuals to live well with ongoing and mostly progressive conditions. An often-cited aim is to provide support that works in partnership with individuals with LTCs, by harnessing and enhancing their own capabilities to self-manage (Entwistle, Cribb, and Owens 2016; Nolte and McKee 2008; Wagner 1998; Dunston et al. 2009). There is evidence that self-management support programmes can improve clinical outcomes and have a positive effect on the activities of daily living (Taylor et al. 2014; van het Bolscher-Niehuis et al. 2016). Although self-management support has been delivered using different approaches based on different models (Pearce et al. 2015; de Silva 2011; Coster and Norman 2009; Barlow et al. 2002; Taylor et al. 2014; Battersby et al. 2010; Lorig 2015), it is articulated in national and international health policy as a way to extend the scope of healthcare delivery for LTCs, give prominence to the needs of people with LTCs and enable the inclusion of the social and emotional aspects of living with LTCs alongside the medical and physical (Entwistle, Cribb, and Owens 2016). Australian LTC policy directs funding to activities of self-management support. Within these policies self-management support is defined as “enabling people with chronic disease to engage in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships, and negotiating and adhering to treatment regimens.”(Australian Government Department of Health)

A common format for providing self-management support for LTCs is through the provision of group programmes, typically facilitated by health professionals such as nurses, dietitians and physiotherapists. Evidence has shown improved health outcomes for condition markers such as blood sugar levels in diabetes, quality of life, health behaviour changes and utilisation of healthcare, although these are not sustained long-term, and tend to show only small-moderate improvements (Deakin et al. 2005; Warsi et al. 2004; Zwerink et al. 2014; Taylor et al. 2014; Lorig et al. 2001; Rogers et al. 2008). In addition, group programmes offer the potential for providing an environment where participants feel supported and heard, can share experiences and gain condition-specific knowledge and strategies for self-management (Stenberg et al. 2016).

Our study of health professionals facilitating group programmes found they conceptualised the provision of self-management support predominantly ‘top down’, with a focus on facilitators providing evidence-based education and instruction for health behaviour change (Hughes et al. 2018). In contrast, our recent systematic review of the experiences of participants in self-management group programs revealed the importance of the social connectedness, support and knowledge received from and shared with other group participants through feelings of belonging, shared learning and comparing experiences (Hughes et al. 2017). What this review also revealed is that ‘support’ takes a variety of forms and what support is valued may differ both between and across facilitators and participants in group programmes. Understandings about the notion of support for LTCs are still not well developed. There are very few specific studies published in this field; most previous studies are focused on explaining outcomes of controlled interventions with single conditions or, on the experience of enacting and sustaining health behaviour change (Hughes et al. 2017). Research has identified that support received and shared between both facilitators and participants during group programmes is valued Hughes 2017. In this study we aim to explore and understand the different types of support that group participants in health professional-led self-management support group programmes receive and exchange and how they make sense of and value this support from both facilitators *and* peers.

*Theoretical framework*

In line with the aims of this paper, we conceptualise ‘support’ using a theoretically derived framework (Cohen et al. 2000, Page 3). This framework suggests the term social support can be understood as encompassing informational, instrumental and emotional support. Informational support refers to information, advice or guidance, instrumental support refers to tangible assistance, and emotional support ‘expressions of empathy, caring, reassurance, and trust’ along with ‘opportunities for emotional expression and venting.’ (Cohen 2004) Thoits (2011) proposes that the support provided by individuals with similar experiences, for example of LTCs, is valued for their direct experiential knowledge and in-depth understanding of the ‘many dimensions and nuances’ of the individual’s situation. Similar others provide information and advice that is relevant, and empathy is expressed because it is drawn from personal experience (Thoits 2011; Kennedy et al. 2007; Koetsenruijter et al. 2016). They can also act as role models for comparison, shaping coping responses and providing hope that proposed courses of action will be beneficial (Thoits 2011; Rogers et al. 2014).

In the context of health-professional led self-management programmes, where there is potential for support from both facilitators with medical expertise and from (patient) participants sharing similar experiences, it is unknown what support provision participants receive and from whom, and what support they value.

# Methods

Approach

This paper draws on semi-structured interview data with individuals who were participating in a self-management group programme for one of three LTCs (chronic obstructive pulmonary disease, diabetes or obesity) to explore the experiences and views of participants about the support they perceived during the programmes. This paper is part of a larger qualitative study conducted in NSW, Australia on the role of goals in chronic conditions self-management. Ethics approval was obtained from area health district and university ethics committees.

The sample

Participants were people with long-term conditions (n=20) attending group programmes. Table 1 provides participant characteristics. The group programmes selected (n=6) were chosen because they provided self-management support for people with one of three long-term conditions: chronic obstructive pulmonary disease (COPD), type 2 diabetes, and obesity. Programmes were from a range of metropolitan and regional locations and hospital and community-based settings. Table 2 provides programme characteristics.

Table 1. 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 |

Table 2. Programme characteristics

|  |  |  |  |
| --- | --- | --- | --- |
| **Site** | **Location** | **Condition** | **Facilitator types** |
| 1 | Large metropolitan hospital outpatient gym | COPD | Physiotherapist |
| 2 | Small metropolitan hospital outpatient gym | COPD | Physiotherapist |
| 3 | Large metropolitan hospital outpatient room | Diabetes type 2 | Dietitian |
| 4 | Suburban general practice | Diabetes type 2 | Dietitian and exercise physiologist |
| 5 | Large metropolitan hospital outpatient room | Obesity | Physiotherapist, nurse, psychologist, dietitian |
| 6 | Rural, community hall / hospital meeting room | Obesity/ healthy lifestyle | Dietitian and exercise physiologist |

Recruitment

A researcher introduced the study to participants during the course of the programme and those who expressed interest were given an information sheet and invited to participate in an interview. All participants were provided verbal explanation about study participation and opportunities for questions were allowed prior to interview and written consent.

Data collection

In-depth, semi-structured interviews were conducted face-to-face (in a mutually agreed location) or by telephone between December 2015 and April 2017. Interviews lasted between 60-90 mins were audio recorded and transcribed verbatim by a professional transcription company within 7 days of each interview. All data were de-identified and participants were allocated pseudonyms.

An interview guide was developed to explore individual perspectives and experiences of participation in the group programmes. The interview guide (see appendix 1) was informed by LTC support literature and a systematic review of the qualitative group self-management programme literature (Hughes et al. 2017), discussed amongst the research team and piloted with a group programme participant. The interview guide was reviewed at regular intervals alongside early data analysis. Participant interview guides covered living with and managing LTCs, reflections on what they gained from the group programme and their experiences of and interactions with group facilitators and other group members and plans for their health.

Data analysis

Qualitative data software (nVivo 11) was used to manage and organise the data. The data were thematically analysed using a combination of deductive analysis using the social support framework (informational, emotional and instrumental), and inductive analysis of the participants’ perceptions of the process of gaining support in the group programmes including any issues they experienced. Interview transcripts were read repeatedly and categorised using the three theoretical component types of support provision – instrumental, informational and emotional – as a framework to consider the support described by group participants (Cohen 2004; Thoits 2011). We were sensitive to descriptions of perceived versus received support; the source of support and; how participants talk about the value and meaning associated with support that they experienced during the programme, and these formed the basis for our thematic analysis. Comparisons and insights within and between interviews informed future interviews as did outlying interview data. During this process we confirmed our interpretations were supported by returning to the original data. The team met regularly during data analysis to ensure consensus and to discuss areas of divergence.

# Findings

Probably because the self-management groups were made of relative strangers, participants discussed informational and emotional but not instrumental support from the group. They also highlighted that although they very much valued time in the sessions for interaction with other group members, these interactions were often shut down or were not encouraged by facilitators. We cover each of these main themes in turn. . Three central themes were derived from analysis. First, group facilitators and group members were seen to contribute different yet complementary forms of informational support for living with a LTC. Owing to the different forms of knowledge that they drew on: facilitators from their professional training and education in chronic condition self-management, and group participants, knowledge gained from their lived experience. Second, participants felt emotionally supported by both group facilitators and other group members, yet they distinguished between the nature of such support. Emotional support from group facilitators was typically more overt or explicit (for example, being encouraged, being listened to, being responsive to their concerns), where, in contrast, the emotional support gained from other group members was more inherent or ‘felt’ (for example, feelings of belonging and acceptance from being among others with similar experiences). Finally, opportunities for peer support through group member interactions, though seen as important to participants, were perceived to be shut down or were not encouraged by facilitators.

## ‘Experiential’ and ‘factual’ informational support equally valid

Participants distinguished between the informational support that was provided by group facilitators (e.g. health education and instruction) and the informational support from other group members (e.g. experiential knowledge, strategies and practical information acquired through living with a LTC). Participants viewed facilitators as possessors of ‘factual’ information about LTC self-management, which they had obtained from professional training and education. Facilitators’ knowledge and advice about managing LTCs was seen as ‘trusted’ and ‘legitimate’, yet also didactic, inflexible, sometimes overwhelming, impersonal or lacking insights into the participants’ world view and lived experience; knowledge which they felt other group members were more able to understand and provide.

Participants positioned the group facilitators as having ‘expert’ knowledge in the self-management of LTCs on traditional medical aspects such as condition physiology, test results, medications and recommended foods and exercises. They appreciated the facilitators’ interest in the field and for having spent time learning and studying. Information and advice provided by facilitators was respected and legitimised by participants (e.g., ‘she has legitimate answers to legitimate questions’ *(Rose, female, age 69, COPD, site 1)*) and thus participants placed a high level of trust in facilitators to provide accurate information and advice that would be in the best interests of group participants. Participants also privileged facilitators’ knowledge by stating that they had ‘the right’ information and would advise the ‘correct’ course of action. This can be seen in the following quote 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 does mobilise the information that he understands and describes this as a strong motivating factor in doing the strenuous exercise the facilitator suggests will benefit him.

*[He 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. I know when I go to the stress test for my heart they want me to push myself, to see the heart racing. And I know, I watch the heart thing on the walking machine, the bike and that, because that to me, I’ve got to get that up. And 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. ...Yeah, I don’t understand all the other figures. He says, “Oh, well, you’ve got to get this level here,” and I don’t know what it’s all about. (Gary, male, age 73, COPD, site 2)*

At times, however, participants perceived that the advice and information provided by facilitators was ‘rigid’, overwhelming (there was ‘too much’ information) or irrelevant to their personal circumstances. The following quotes illustrate how this top down, one-way delivery of information led some participants like Dan to disengage:

*This is a very formal, a more rigid educational [programme]...They're not finger waggers, 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, male, age 52, obesity, site 5)*

*There's a lot of information, and you have to actually sit there and sort of...I don't know. [It’s] interesting. I don't know if it’s a bit more problematic as opposed to helpful, in that...well maybe bombarded with a lot of information. Maybe eventually it will sink in. As I said I'm still coming. There's a lot there, you've got to actually then go home and maybe review it, which I haven't been doing. (Anna, female, age 52, obesity, site 5)*

We can also see from Dan’s quote that when the group facilitator is positioned as high status or authoritative this can be problematic, because it can impede group participants from being involved in the production of knowledge about their condition and in the ‘discovery’ of ways to self-manage. Participants felt like passive recipients of information – ‘we just sit and listen to what he says’ (Ken, male, age 79, diabetes, site 4). However, they wanted their own expertise and capabilities for independent learning recognised and integrated into sessions. Fred, for example exclaimed ‘we’re not kids’ and suggested many aspects of the information provided by facilitators was common knowledge. This is suggestive that facilitators may be making assumptions about (and thus underestimating) the level of information participants in programs have and this is likely to have negative consequences for informational support they provide participants, as illustrated in the following indicative quotes from Fred and Monica:

*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, male, age 72, diabetes, site 4)*

*I think it’s given me more knowledge. But then I think like I said, the knowledge was there. (Monica, female, age 36, obesity, site 6)*

In contrast to the informational support provided by facilitators, participants described the value of information gained from the other group members because of their experiences of managing their LTC(s). They described this experiential knowledge as equally valid yet different to the information provided by facilitators, as it was more personally relatable and relevant to participants’ own circumstances, needs, experiences and challenges. Participants talked at length about the importance of learning from other group members about their strategies and approaches to self-managements because they shared similar conditions and struggles. They identified this as a key ‘gap’ in the informational support that was provided by group facilitators, who could provide more generic information, but did not have the knowledge about the intricacies and specificities of living with a LTC, and the complexities involved in trying to self-manage. For example, Kevin talked about his belief that health professionals present them with ‘no choice’ but to follow a restrictive diabetic diet. Yet, despite displaying empathy with patients, health professionals are not fully aware of how burdensome it is for people with diabetes to adopt and sustain such a diet. In contrast, he talked about the shared ‘understanding’ of others living with diabetes and how information rooted in lived experience is ‘more believable’.

*Doctors who don’t have cancer, dealing with a patient who does can empathise all they want, but they don’t know what it’s like so…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 language, there’s an understanding that we don’t have to say everything to understand what it’s about. And when you say, when they can sit there and say look I know what you’re going through, well they do. And that’s accepted...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, and it’s a difference…it is harder for someone to do because they have to. (Kevin, male, age 62, diabetes, site 3)*

Bill similarly revealed how he listened to the accounts of other participants’ experiences from the group and the reactions and responses of the facilitator to these experiences to form his understanding. He described how he characterised the information from different sources into ‘practical’ knowledge from participants and ‘theory’ from facilitators.

*you’re 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 her [the facilitator], but the practical stuff from other people. (Bill, male age 31, diabetes, site 3)*

Participants provided further examples of how they viewed themselves as capable of filtering information and choosing what was valid and useful to them whether it was from facilitators or from other participants. Rose spoke about how she utilises information from others to trigger self-reflection and further inquiry on her self-management or discards it:

*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, female, age 69, COPD, site 1)*

## Overt and felt forms of emotional support are valued

Participants perceived that they were emotionally supported while participating in their group programme, and they described the group environment as ‘welcoming’, ‘comfortable’ ‘safe’, and ‘reassuring’. There were notable differences in the nature of emotional support participants described receiving from group facilitators versus other group members. The emotional support they received from group facilitators was more overt. In contrast, they described *feeling* emotionally supported by other group members, who shared similar experiences, even though interactions between group members were limited.

The emotional support provided by facilitators was characterised by participants as being ‘personable’, ‘empathic’, ‘encouraging’, ‘attentive’, ‘positive’ and non-critical or -judgemental. Facilitators were said to be ‘really there…going…“come on”’ yet, also ‘kind’, ‘thoughtful’ and they ‘accounted for everyone’s problems’. Relationships with facilitators were described as trusting and non-threatening and many emphasised that they were treated as a ‘person’ rather than a ‘patient’ (in contrast to how they described being treated by other health professionals in their one-to-one consultations). For example, participants like Monica, said they could confide in and ‘disclose anything’ to their facilitator knowing they would be listened to and supported.

*I can tell them anything. I confide in them. 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, female, age 36, obesity, site 6)*

Participants also felt comfortable to expose their vulnerabilities or fragilities, without fear of being shamed, embarrassed or criticised – something that they feared or had experienced in other spaces. This is illustrated by Rose, Mark and Gary who each talk about the reassurance gained from knowing about some of the more social, but also commonly experienced, impacts of living with their LTCs:

*I can ask her [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, female, age 69, COPD, site 1)*

*I find them [facilitators] wonderful, you know extremely experienced, encouraging, they treat people as individuals, it’s…they remember things, they know a little bit about every person’s life and are able to make them feel welcome by remembering them and asking them about it, you know, they’re very good. ...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, male, age 68, COPD, site 1)*

*Having someone like [facilitator’s name] there, who’s really helpful, and not pushy and critical, and you know he lets people work at their own level…the way he handles people that are more critical than I am, I think, but he’s very gentle and caring with them. He pushes, but so gently they’re not even aware they’re being touched, put it that way. (Gary male, age 73, COPD, site 2)*

In contrast, the emotional support exchanged between group members was rarely overt. Apart from a couple of instances where participants gave examples of explicit acts of emotional support from other group members, mainly encouragement during exercise activities for those groups that included exercise, in most cases, participants described emotional support from other group participants as *felt* or implicit, or in the words of Gary, ‘subliminal support…you’re not conscious of supporting someone or being supported’. This was expressed as a feeling of being among peers who were similar to them because of their shared experience of living with a LTC. Knowing their peers faced similar challenges and ‘struggles’ was described as a ‘leveller’ and led to feelings of inclusivity. Perceiving no hierarchies, unlike with facilitators who were placed in positions of authority, made them feel safe, and contributed to an environment that was ‘not threatening’. Even though this was not demonstrated explicitly, participants felt that their peers had non-judgemental attitudes because of their shared experiences, and this had contributed to an open and inclusive setting, as illustrated in the following quotes:

*What I get out of it is if I'm in a group that 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, I know that it's not just me…[With other people] well sometimes if I look at it like am I not good enough for them...do I look like I'm a lazy slob. When I'm with someone that's training. The negative people I'll put it down to. But if I'm with the ones that are positive...they're [other group 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. …Like not just giving me support because they feel pity for me. (Ruby, female, age 27, obesity, site 6)*

*You don’t go there to judge either. We’ve all got the same problems, we’ve all done things that have got us there, or our health has got us there because of certain reasons, we’re there, and our age. (Paul, male, age 60, obesity, site 6)*

*You seem to make friends very quickly; people tend to open up very quickly…I feel you’ve got to be supportive of each other. And they’re all nice people, and we’re all there for the same reasons. 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 male, age 73, COPD, site 2)*

*I’m not alone and people struggle with similar things that I struggle with. (Kevin, male, age 62, diabetes, site 3)*

The sense of belonging and being accepted by the group, an opportunity not always presented outside of the group, allowed participants to compare their situation to others and led to feelings that they were ‘not alone’, that their experiences of illness were ‘normal’ and shared by others. For many, such as Fred, this was the first time they felt normal. Others, such as Deb alluded to the hope gained from seeing others with similar experiences and symptoms, ‘doing well’ or ‘improving’:

*Most things that [group members] Ken and Michael said that they do, I’m about the same. I’m the same myself. [So how does that make you feel, being with others that have similar experiences?] I love being with people. …Makes me feel that I’m normal…that I’m the same as other people…[Is that different to if you’re just by yourself with a doctor?] Yeah. It’s much different. Because when you’re with people you say things that you…when you’re with the doctor, he’d ask you, say, ‘how’s your blood pressure been?’ Or check your blood pressure. But being with, as we were in a group, I like it. (Fred, male, age 72, diabetes, site 4)*

*It’s really good, when I see people improving and I can see how they get better and better and I’m like that’s really good, I’ve got to do a bit more. Yeah, it is good. So that’s the other good thing about being in that, with people that are like you, cause you see them improving. (Deb, female, age 69, COPD, site 2)*

*I think 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, male, age 68, COPD, site 1)*

Participants also described being able to express their feelings and emotions to an understanding audience. They felt understood when expressing their frustrations aloud and confident the response of their peers in the group would be unaffected and accepting. Mark talked about being ‘allowed’ to express how he felt when among peers:

*A lot of it’s sort of like, 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, male, age 68, COPD, site 1)*

*Oh people will say things like oh this, you know “I don’t know how I’m ever going to get through this”, you know blah, blah, blah, but during the chatting they get through it. So I think subliminal support, yeah, is what I’d put it down to. You’re not conscious of supporting someone or being supported but the little conversations, the little bits of you know oh yeah I was like that yeah when I first started. It’s all helpful, yeah. (Gary, male, age 73, COPD, site 2)*

*I lacked the motivation and that’s probably how they are [other group members]...we’re all in the same boat. We all have the same health issues, and maybe what I said, that motivation. Yeah, I think that’s the key. Like I said, left to myself, I don’t do it. (Jill, female, age 65, diabetes, site 4)*

## Opportunities for peers’ support through group interactions are constrained

Participants revealed that interactions between peers in the groups were not promoted by facilitators and thus there were few interactions, or these interactions occurred ‘ad hoc’ for example, fitted in between what was otherwise directed closely by the facilitators. Most participants felt they would have gained from more opportunities to hear from, and talk with, peers. A few however, said they actively avoided interactions with others in the group because this might trigger negative emotions that they perceived were unhelpful for them. When participants reflected on their experiences of participating in the group programmes they described little actual interaction between group participants, and few opportunities available or time allocated to do so. The facilitators or programme structure seemed, from the perspective of participants, to shut down or limit opportunities for group interactions, and instead prioritise individual activities (exercises or workbooks) and facilitator directed aspects of the programmes such as education and instruction. Support from peers, spoken about at length as important, appeared to be bracketed off from or invisible to facilitators, who were described as not giving opportunities or space for group interactions or at times were active in shutting down interactions. Anna below, perceived facilitators were discouraging of group interaction by not providing opportunities in the programme and she questioned their motives for configuring the room in rows, not facing each other. Mark and Deb even questioned whether their programmes could be described as a group, Deb stating she had little knowledge of the other participants.

*It's not set up...like the way the room is set up. Even if it was just set up like that…there'd be... 'cause you'd be looking this way….just looking forward. Yeah. 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, female, age 52, obesity, site 5)*

*It’s a group but it’s not a group. Because there have only been one or two occasions where we’ve done things together. (Mark, male, age 68, COPD, site 1)*

*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, female, age 69, COPD, site 2)*

Participants felt they were restricted in their opportunities for discussions and wondered what might have been missed from not having opportunities to listen to others. As well as hearing different information and strategies on managing their conditions, participants would also have liked to have heard more of others’ feelings and their experiences of coping. They suggested through hearing about the struggles of others they could view their own in context and thus perceive themselves more favourably:

*I come there and I’m thinking gee I’ve had a bad week, I’m struggling. And just to hear someone else is struggling would probably make me feel a bit better in myself. Not saying it’s a good thing that we’re struggling, but yeah. It would lift my spirits to say that I’m not actually failing. (Monica, female, age 36, obesity, site 6)*

*I suppose I feel a bit more...it's more normalised. You're actually meeting...Well they're real people. …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, male, age 52, obesity, site 5)*

*[So with that in mind do you think there was enough group interaction?] No I don’t. And I think a lot of that was generational. You know believe it or not. I think that Bill being younger interacted more with the males and Kevin but Anne was very quiet but maybe I’d say she is a shy-ish type of lady you know. Yeah I didn’t think the interaction was great. I didn’t think it was real bad but I thought it could have been better. [Like how could it have been better, what would really get that interaction going better?] I think [Facilitator’s name] should have asked more questions to each person personally like for example I think she should have went around the table and for example said to Joe “so Joe how like you said how do you feel about being diagnosed with diabetes?”. (Hazel, female, age 69, diabetes, site 3)*

A few participants also felt there was an absence of opportunities to directly express how they were feeling and coping to other participants, though they believed this would have a positive impact on their emotions. For example, Rose, spoke about following her regimen solo but had regrets about the supportive benefits she felt she had missed out on. Warren, was willing to come early or stay back to be given this opportunity:

*Well 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 group facilitator] if there’s a problem, but nine times out of ten I just come in and do my own stuff, right, because I know what I’ve got to do, and I know the exercises and things. …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, female, age 69, COPD, site 1)*

*I reckon 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, male, age 33, obesity, site 6)*

A few participants spoke of their reluctance to share their experiences with their health condition, and yet, still valued the ‘little chats’ they had with peers in the group about their daily activities and common interests. These participants avoided talking about their LTCs, in part, because they wished to avoid negative emotions that this could trigger for them. 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, to me it’s important. …It’s just nice to meet new people… and we’ve got that in common. 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. Everyone’s there, I mean we know why we’re all there. We just chat about other things...about life. ...No you don’t talk about your illness. (Gary, male, age 73, COPD, site 2)*

*I mean not everyone wants to talk about their issues either. … I mean most group things that I've done, or courses I usually end up meeting people and making friends, but this is going to be different. … It's too close to home, too many people with the same problems here. (Anna, female, age 52, obesity, site 5)*

# Discussion

This is the first study to explore the perspectives of the participants of a diverse range of health professional-led group programmes providing support for LTC self-management, about the support they received. Applying a social support theoretical framework 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 and that they perceived this support as different according to its source. A key aspect of this finding is that participants considered both sources of support as valid and important, and having both meant gaining a broader range of support than they had found 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 the right or legitimate answers to participants, whereas from other participants it was grounded in lived experience and rich with opportunities for knowledge 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 (Borkman, Ziebland 2012, Allen 2014). Indeed, governments and other organisations have themselves become promoters as the evidence for benefits have increased (Ziebland 2012). What our study adds, is that participants of formal self-management programmes led by health professionals valued both professional expertise and experiential knowledge in the same place, as this enabled them to compare and form their own broader and more complete representation of knowledge (Leventhal). Further, the perceived limitations of both health professional facilitators and of other participants are reduced by the presence of each other.

As with informational support, emotional support that enabled participants to feel safe and reassured also differed by source. Emotional support from facilitators was perceived as overt and attentive, providing professional care and encouragement to participants, 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 support, such as was spoken about by the group participants in relation to emotional aspects of support, is (paradoxically) stronger and more consistently beneficial to health than received (overt) support (Cohen 2004). Support from similar others is believed to directly affect physical and mental health and indirectly buffer harmful physical and mental effects (Thoits 2011) and this was evidenced in the participants’ responses. Further, deliberate (received) support can promote feelings of indebtedness, being unjustly overrewarded, dependence, loss of control or incompetence (Thoits 2011). Our study participants’ responses were about the value of having emotionally ‘safe’ opportunities to chat with and observe others, and there were a number who spoke about the emotionally supportive value of 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 (Allen, Ziebland).

Studies of group self-management participants’ experiences have previously provided isolated reports of limited opportunities in programmes to interact with their peers (Hughes et al. 2017). Our study explored this in more depth and found participants sought the support that comes from listening to others’ struggles, from sharing your own frustrations with an understanding audience, and from hearing how others have managed. The participants were very clear that these supportive processes were unique to being with similar others and that a positive emotional benefit was a direct result i.e. health professionals were not mentioned as being able to provide this aspect of support. Explanations for why health professional facilitators did not prioritise this may be found in previous research that has revealed preferences for professional authority and evidence-based education over lay experience as well as narrow biomedical conceptualisations of self-management support (Hughes et al. 2018; Morgan et al. 2016). There is also evidence that health professionals fit self-management support around clinical activities and roles perceived as more important (Sadler et al. 2014), that there is little group-specific training of health professional facilitators (Hughes 2017) and uncertainty from health professionals around where to prioritise their self-management support efforts (Hughes 2018).

Our study has highlighted that the group participants perceive a scarcity of opportunity for gaining support from similar others in their regular lives. Within the constraints for interactions between peers described, participants nevertheless found some opportunities from the other group participants to fulfil broader informational and emotional support needs, a highly valued aspect of the group programme and fundamental to gaining the psychosocial benefits that participants say really mattered to them. The participants in our study revealed they had compared themselves with others, self-reflected, role-modelled behaviours, regained feelings of normality and perceived a greater sense of hope. Through these processes of perceived support from others they spoke of feeling more motivated and engaged with their health. These outcomes contain aspects that should be of interest to researchers, practitioners and policy makers in the ongoing quest for patient engagement and activation with self-management (Australian Health Ministers’ Advisory Council 2017; Hibbard J and Gilburt 2014).

Strengths and limitations

We purposively sampled in order to gain breadth and richness of experience. Limitations in our study were that participants self-selected into our study, and this may mean that other viewpoints were not captured in our data, such as those who feel group self-management is unsuitable, who dropped out of the programme or were less engaged. A further limitation is that only one interview was conducted per participant, future studies may wish to explore other group programme settings and use multiple time points before, during and after programmes.

Implications for clinical practice

Participants exposed some of the limitations of formal self-management support that is provided by health professionals in group programmes as well as some opportunities. The groups 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 (Taylor et al. 2014; Hughes et al. 2018). Practitioners facilitating group self-management support programmes must be aware of the limitations inherent in professional expertise revealed in this study to people seeking support with self-managing LTCs. Allowing space for the invisible support of peers and promoting experiential knowledge should make group self-management support more relevant to participants and 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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Appendix 1. Interview guide questions

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| --- |
| 1. Living with a LTC

Tell me a bit about yourselfWhat kind of things do you do to manage your condition?Has the way you manage your condition changed over time?1. 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?1. 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 [ ]?  |